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ABSTRACT

This final report describes activities and accomplishments of a federally supported program to provide services for children with deaf-blindness in Missouri. The project focused on the development, implementation, and evaluation of a four-component statewide comprehensive service delivery model to serve 193 deaf-blind children and youth through: (1) early education, family-focused models, and technical assistance; (2) the Curriculum Specialist project; (3) the Family Life Cycle Support System; and (4) planning for transition and adult outcomes. Annually, approximately 45 families of infants and toddlers received direct weekly home intervention. In addition, "parent advisors" received training, early childhood specialists completed relevant coursework, and respite care orientation training resulted in an increase in number of consumers utilizing this service. Technical assistance and inservice training were provided for professionals, paraprofessionals, and parents. A pilot partnership to develop local capacity in St. Louis (Missouri) for supported living was initiated. New partnerships were formed and old partnerships strengthened through interagency collaboration efforts. Team building and strategic planning for integration were carried out by statewide team action planning groups. Materials provided at a workshop on deaf-blindness and a training module on developing communication for children and adults with deaf-blindness are appended. (DB)

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307.11 State Project, Services for Children with Deafblindness in Missouri

FINAL REPORT
Fiscal Year 1994-1995

Office of Special Education Programs (OSEP)
Office of Special Education & Rehabilitation Services
U.S. Department of Education
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II. ABSTRACT/EXECUTIVE SUMMARY

307.11 State Project. Services for Children with Deafblindness in Missouri

The project "Single State Center for Services for Children and Youth with Deafblindness in Missouri was designed to refine and solidify a service delivery plan that responds to the priorities described in the Federal Register in 34 CFR 307.11:

1. Provide direct services to children with deafblindness for whom the State is not obligated to provide these services under Part B of the IDEA or some other authority. 307.11(a) (1)

2. Provide technical assistance to families and to State, public and private agencies which are providing early intervention, educational, transitional, vocational, early identification and related services. 307.11(a) (2)

3. Provide the coordination of services to assist in the transition process. 307.11(f)(1) and (2)

The goals, components and activities of the Project focused on the development, implementation and evaluation of a four-component Statewide comprehensive service delivery model to serve 193 deafblind children and youth:

I. FOUNDATION FOR EDUCATION
II. FAMILY LIFE CYCLE SUPPORT SYSTEM
III. FOUNDATION FOR TRANSITION
IV. PLANNING FOR TRANSITION AND ADULT OUTCOMES

The Project implemented an adoption model of the INSITE project called MoSPIN. Annually, approximately 45 families of infants and toddlers received direct weekly home intervention. Fifteen new professionals called "Parent Advisors" received training, adding to a total of 38. The Project built local capacity in early childhood by providing VIISA training. Fifteen early childhood specialists serving 85 pre-schoolers completed VIISA coursework for credit annually.

A Respite Care Model was implemented. Respite Care orientation training was provided resulting in a 15% increase of deafblind and severely handicapped consumers utilizing the service each year.

Technical assistance and inservice training was coordinated for an average of 500 professionals, 40 paraprofessionals and 50 parents in basic skills and deafblind methodology each year.

Families, consumers and service providers were assisted in the transition process by ongoing intensive skill development.

A pilot project to develop local capacity in St. Louis for supported living was initiated. Twelve individuals received assistance in living placements and training was provided to the adult service providers.

New partnerships were formed and old partnerships strengthened through interagency collaboration efforts speared by the State-level Deafblind Task Force. Four local task forces were developed (St. Louis, Kansas City, St. Joseph and Mid-Missouri). Human and financial resources were pooled resulting in multi-funded activities for staff training and service provision Statewide.

Team building and strategic planning for integration were the primary targets of the Statewide team action planning groups. One-year goals were monitored by Project staff each year.

Products that were developed included a Transition guide and an information module on Transition, Deafblind Introduction Training modules and bi-monthly project newsletters. The Deafblind Project Coordinator also participated on the Perkins National Deafblind Training Consortium which developed proposed deafblind teacher competencies to be submitted to the Council of Exceptional Children (CEC).

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IV. Goals and Objectives of the Project

The eight principle Objectives of the Project were:

OBJECTIVE 1. To provide a Statewide outreach and home intervention program to children who are deafblind (birth to 5 years of age) and their families.

OBJECTIVE 2. To administer a Respite Care program and act as a resource to other respite care programs serving persons with deafblindness.

OBJECTIVE 3. To provide technical assistance to families and to public, private and State agencies on basic skills, sensory training, technology, best practices, transitioning, family dynamics and respite care orientation.

OBJECTIVE 4. To provide information assistance to families, SEAs and LEAs on basic skills, sensory training, technology, best practices, transitioning, family dynamics and respite care orientation.

OBJECTIVE 5. To improve consumer/family input in the transition (IFSP, IEP) process.

OBJECTIVE 6. To document adult outcomes as designed in the transition goals.

OBJECTIVE 7. To cooperate and coordinate the delivery of services with other related State, federal and local agencies.

OBJECTIVE 8. To support a parent-to-parent outreach network.

The operation of this Project was administered and coordinated by Missouri School for the Blind, a direct extension of the Missouri Department of Elementary and Secondary Education, Division of Special Education. Objectives and activities were carried out by a collaborative agency effort among Missouri School for the Blind (MSB), CISE (formerly Missouri LINC [MoLINC]) and the Family Institute of Kansas City, Inc. (FIKC).

Personnel on this Grant who were responsible for accomplishing these Objectives were:

Yvonne Howze, Project Director	.05%	12 months
Linda Van Eck-Niedringhaus, Project Coordinator	100%	12 months
Linda Bradley, Curriculum Specialist	10%	10 months
Jan Rodgers, Family Services Coordinator	50%	12 months
Larry Rhodes, Transition Planning Consultant	100%	12 months

V

COMPONENT I

Project Coordination of Early Education, Family-Focused Models and Technical Assistance

FINAL REPORT

October 1, 1994 - September 30, 1995

Linda Van Eck-Niedringhaus, Project Coordinator
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INTRODUCTION

The following final report is an update and summative accounting of the activities of Component I of the Missouri Deafblind Project for the period October 1, 1994 to September 30, 1995. It is intended to give quantitative and qualitative information about the six Objectives of the Deafblind grant in which the project coordinator shares responsibility with other Missouri Deafblind Project staff:

OBJECTIVE 1. To provide a Statewide outreach and home intervention program to children who are deafblind (birth to five years of age) and their families.

OBJECTIVE 3. To provide technical assistance to families and to public, private and State agencies on basic skills, sensory training, technology, best practices, transitioning, family dynamics and respite care orientation.

OBJECTIVE 4. To provide information assistance to families, SEAs and LEAs on basic skills, sensory training, technology, best practices, transitioning, family dynamics and respite care orientation.

OBJECTIVE 5. To improve consumer/family input in the transition (IFSP, IEP) process.

OBJECTIVE 7. To cooperate and coordinate the delivery of services with other related State, federal and local agencies.

OBJECTIVE 8. To support a parent-to-parent outreach network.

ACTIVITIES

1. Delivery of the INSITE Family-Focused Model to Children Birth to 5 Years and Their Families

The 6-day INSITE Training to 15 new Parent Advisors was conducted in November and July. As a result, 10 new families were provided a weekly home intervention program using the INSITE curriculum through the MoSPIN program. An average of 45 families of infants and toddlers were served each year. Services included weekly home visits to help families understand their child's visual impairment, the impact this disability may have on their child's development, and ideas/techniques for providing a stimulating environment for their child. Parent Advisors also assisted parents to connect with various resources and services. Interagency linkages through First Steps and assistance in the transition from home to LEA early childhood special education programs were provided. Parent Advisors accompanied and assisted families as participants on IFSP and IEP teams. In addition to weekly lesson plans, children in the MoSPIN program were assessed in both the INSITE Checklist and Callier Azusa Scale for Utah State University tabulation. Further, Orientation and Mobility assessments were provided by Missouri School for the Blind Outreach Division staff when referred.

The INSITE curriculum manuals Volumes I and II were transcribed into braille totaling 40 volumes per set during year one of the project. Adding this medium to the current collection of INSITE curriculums on cassette tape made the INSITE training more accessible to those participants who are blind.

This activity addresses Objectives 1,3,4,5.

Impact

The average MoSPIN child showed accelerated growth during INSITE Model intervention in all developmental areas surpassing maturation and individual developmental rate. Proportional change indices on the Callier-Azusa Scale ranged from 1.1 months for Social Development to 3.5 months for Daily Living.

Families became effective, informed advocates in the special education process, which resulted in smoother transitions from home to school.

A MoSPIN Family Survey has been used to elicit feedback from participants. In the most recent survey, parents expressed a high level of satisfaction with MoSPIN services and they specifically noted an increased understanding of their child's unique needs. Other comments focused on their own personal growth, increased acceptance of their child, improved parenting skills, positive changes within their family, better understanding of the "system" and their rights and responsibilities, feelings of empowerment and delight in the growth and development of their child. The following anecdotes were shared by parents and their Parent Advisors relative to the impact of the MoSPIN family-focused program:

Highlights of what parents liked best about the MoSPIN program

"I've learned lots about my son's visual impairment."

"After our visits I felt I was in control and on the right track and doing a good job caring for my daughter's needs."

"The information I've been given has been very helpful - I've been given ideas I would never have thought of."

"The checklist gives me ideas."

"Help understanding the medical part - looking up and explaining terms."

"I better understand how (my child) does see."

"My child uses her cue to let everyone know she wants to be picked up."

"The curriculum is good, and I like the checklist. It gives me an idea of where my child is and helps me get through the "mother's pride" to reality in assessing my child's strengths and weaknesses."

"I was thrilled to have my child respond to Christmas lights. Last year, she didn't even know they were there."

"It was wonderful to have help when it came to dealing with the doctors, because that was my area of greatest frustration."

"Ideas on stimulating vision."

"I have really enjoyed this service."

"I am more aware of providing stimulation in everyday living."

"The information has been very beneficial to use and the lessons were geared toward the questions and problems that we were having at the time."

"The ability to learn different things and help my child excel to his best abilities."

"We have since realized that there are many ways to learn."

Highlights of what parents liked best about their Parent Advisor/visits

"My Parent Advisor is teacher, mentor, friend, coach, cheerleader. I think she is wonderful!"

"I look forward to my Parent Advisor's visit, not just for the information, but for fun and friendship."

"She comes ready to help."

"My Parent Advisor takes the time to explain things I need to know and makes it seem easy."

"She is the best!"

"The emotional support."

"I had someone I could talk to and understand about his vision."

"She is one of the few people I can talk to who understands."

"Having a blind child carries many emotions and questions and it is good to have someone there."

"Someone understood what I was going through and dealing with vision impairment."

"Our Parent Advisor has provided valuable information for my husband and me and has been a great support!"

"My Parent Advisor is the best person I've seen in any program."

Highlights of how the program could be improved

"Nothing negative to say."

"The MoSPIN Project and my Parent Advisor have been so helpful and informative and such a big support - I do not feel it needs improving in any way."

"We get everything done we are supposed to."

"I can't imagine changing anything with her."

"I would like a chance to meet with other parents in the program."
"If they had more time with each parent."
"Maybe we could get together more often."
"Wish we knew about the program earlier."

Data of an increased understanding of:
- visual impairment - 100% said yes
- implications of visual impairment - 100% said yes
- environmental factors - 100% said yes
- providing a stimulating environment - 93% said yes
- selecting toys - 100% said yes
- importance of play - 93% said yes
- importance of social interaction - 93% said yes
- how motor/hearing affects child - 93% said yes
- improving communication - 100% said yes
- how my child communicates - 100% said yes
- child's feelings and needs - 100% said yes
- how to find help and special services - 93% said yes
- how to share my feelings and needs with family and professionals - 100% said yes
- how to "cope" - 100% said yes
- how to work with my school district to get appropriate services - 100% said yes
- the IEP or IFSP process - 93% said yes

A new component was added to MoSPIN this year. "PARENT TIME," a newsletter written and edited by a parent participating in MoSPIN, was sent quarterly to parents and Parent Advisors. This newsletter provided a vehicle for sharing information regarding: 1) toys and materials; 2) resources, services, conferences and organizations; 3) problems and solutions; 4) helpful hints and tips from other parents; 5) working effectively with professionals; 6) accomplishments and success stories (bragging time!). "Parent Time" was enthusiastically received by parents who enjoyed reading each issue, submitted articles and used the newsletter as a networking tool for connecting with other families with similar needs. Parents reported that the newsletter helped them "know that I'm not alone" and that there are other families that also have a child with a visual impairment.

In summary, the benefits to the child's growth and development met or exceeded expectations. Beyond this, the integrity of the parent/child bond was preserved. Parents enjoyed their children and saw them as a "baby" first, not as a child with disabilities. Dads were actively involved in child observation activities and play.

*Number of children served (by age):

2	Less than 1 year old
7	1 year old
6	2 years old

7	3 years old
9	4 years old
11	5 years old
42	Total

2. Southeast Regional SKI*HI/INSITE Parent Advisor Conference

Every two years, the statewide early intervention programs for families of children (0-5 years) in the states of Missouri, Arkansas, Kentucky, Tennessee, Louisiana, Mississippi, Alabama, Georgia and Florida collaborate in a regional conference. All of these programs have adopted the SKI*HI and/or INSITE family-focused models. In September 1993, the Project Coordinator, Lead Parent Advisor and the Transition Planning Consultant, along with the Outreach Director from Missouri School for the Deaf, conducted a conference planning meeting with the administrators from the southeast states. The result was a 2-day conference held in St. Louis, Missouri on June 17 and 18, 1994. The Project Coordinator was responsible for securing hotel, audio-visual and program arrangements, developing the conference program and monitoring finances.

This activity addresses Objectives 1,3,4,7,8.

Impact

A total of 107 Parent Advisors providing home intervention to more than 1,000 families in 16 states received state-of-the-art information in several critical areas of the family-focused home intervention model. Parent Advisors and administrators had the opportunity to share ideas and experiences with peers from other states. Topics that were targeted directly responded to competency needs identified by Parent Advisors.

Families accrued benefit from their Parent Advisor who applied new skills acquired in training. One family of a 2-year-old boy who is deafblind, participated in a conference demonstration whereby their son was assessed by Kat Stremel and a communication program was developed with Kat, the parents and the teacher. This communication program is being monitored for follow-up assistance.

In the spring of 1995, each state that participated received a workshop evaluation summary, cracker barrel summary and tips, and copies of those presentations which were videotaped. Further, the succeeding host state, Florida, was briefed by the Missouri project to ensure a smooth replication of the Southeast Conference in August, 1996.

3. Adoption of the VIISA Early Intervention Model

Missouri was one of ten states that was selected to participate in the pilot VIISA Project, a national inservice model for early interventionists and early childhood specialists working with children from birth through five who are visually impaired. Twenty-five professionals attended onsite classes at

Missouri School for the Blind and completed 9 home studies resulting in 4 hours college credit through Utah State University. The instructor was Deborah Chen, Ph.D., California State University, Northridge. The first course "Early Intervention for Infants and Toddlers with Vision Impairment and Their Families" was offered in year one. The second course, "Serving Preschoolers (3-5) with Vision Impairment in Center-Based Settings" began in September 1993 and was completed in November 1993.

Four graduates, who had completed both VIISA courses, participated in a local trainers' training in October 1994 lead by Deborah Chen and Linda Van Eck. As a result, course one was replicated and attended by 15 new early interventionists in 94-95. Course two will be replicated in March 1996, furthering local capacity building.

This activity addresses Objectives 1,3,4,5,7.

Impact

The VIISA training enhanced knowledge and competency for early childhood specialists Statewide in the area of vision. We believe that as many as 60 infants, toddlers and preschoolers who are visually impaired will accrue direct benefit in both home and local school settings. In the self-evaluation process, participants noted greater confidence in meeting the unique needs of this population, a greater appreciation for building family partnerships, and an expanded knowledge of Statewide resources. One-hundred percent rated the instructor, Deborah Chen, as "awesome," the highest indicator. Ninety-Five percent rated Ann Rutherford, who replicated Course One, as "excellent."

The VIISA training has made an impact in building local capacity in those communities served by the participants. All have their own caseloads of children and families, some function as itinerants and consultants. A proposal was submitted to the Part H Coordinator and approved to further build local capacity by participating in a VIISA trainers' training. Funds were secured from Part H to keep the momentum of the VIISA program alive through replicated coursework by local training teams.

4. Replication of the Missouri Respite Care Model

In January 1993, staff from the Minnesota Deafblind Grant Project met with the Missouri Deafblind Project staff regarding potential replication of our Respite Care Model. Operational procedures, processes and systems were discussed regarding referral, orientation training, multi-agency funding, recruitment, supervision, evaluation and dissemination.

This activity addresses Objectives 2,3,7.

Impact

Facets of the Missouri Respite Care Model may be implemented in the Minnesota Model where applicable.

5. Technical Assistance and Inservice Training

In addition to the training provided on early childhood, the Project Coordinator coordinated training to an average of 500 professionals, 40 paraprofessionals and 50 parents each year, impacting the instructional programs of 193 children and youth who are deafblind. Technical assistance was delivered through a variety of formats: onsite consultation; inservice training; workshops; resources; and satellites covering topics matched by identified individual needs. The most systematic format was the Team Action Planning approach. Teams from Statewide programs met and through a force field, likelihood/impact analysis identified one-year program goals. Under the direction of Joan Houghton, Helen Keller National Center - Technical Assistance Center (HKNC-TAC), and Deafblind Project staff, strategic action plans were developed.

Workshop topics addressed in the 3-year period included: Psycho-educational Assessment of Blind, Multihandicapped-Blind and Deafblind Learners (Dr. Harvey Mar); Cortical Vision Impairment (Mary Morse); Transition (Marci Soda); Task Force Development (Jane Everson); Orientation and Mobility (Joan Houghton); Communication Approaches (Stephanie MacFarland); Team Building (Patrick Swarz); Orientation and Mobility (Butch Hill); Socialization (Sharon Sak); Grant Writing (TRACES).

This activity addresses Objectives 1,3,4,5,7,8.

Impact

Team Action Plans focused on team building, team collaboration and integration. The effects of these plans will be monitored throughout the duration of the Project. Already, individual school teams are meeting weekly or at least monthly and including the parents in planning and decision-making. Team building is evidenced also by equalized active participation.

Two pilot sign language clubs were started, one in Springfield and one in Arnold. As a result, each club meets weekly to learn the sign vocabulary of the integrated student. One-hundred and ten third and fourth graders are actively involved in the sign language clubs. Enthusiasm and motivation is high, and social friendships have been formed. One girl who is deafblind has been invited to a slumber party!

The Parent Perspective

"The MSB project staff have been extremely supportive to our local school district. For the first time I felt someone really likes my child."

"The Deafblind Grant staff have helped provide training to our staff who would not have otherwise received this information."

"My daughter, through the use of her auditory trainer, has some intelligible speech."

6. Interagency Collaboration

The Missouri State Task Force For Persons Who Are Deafblind met bi-monthly. Attendance, commitment and plans have been strong. The State level task force is evolving and a new three-year plan was developed in October 1995. Local level task forces with individual student focus were developed in St. Louis, Kansas City, St. Joseph and Mid-Missouri (Columbia).

This activity addresses Objective 7.

Impact

New partnerships are forming with local and State agencies: Life Skills; Bellefontaine Habilitation Center; St. Louis Public Library; ADA. Old partnerships are being strengthened and better defined: The Rehabilitation Services for the Blind; Department of Mental Health. Multi-funding support has been committed for projects: SKI*HI; Part H and 619 for VIISA training; Productive Living Board and SB40 for a pilot supported living project; Helen Keller National Center for adult service provider training; and Medicaid for therapy and equipment at home. No one individual agency can provide the array of services needed. Pooling human and financial resources can make a tremendous impact. Project services are listed in the Statewide directory, INFORM.

An Educational and Transition "Best Practice" Guidelines For Students and Young Adults Who Are Deafblind was developed by staff members from HKNC-TAC and members of the Missouri State Task Force. The purpose of the document is to guide educators and families in monitoring the completion of referral, assessment and educational activities as a student transitions through the school years to adult services.

7. Mentor Training and the Perkins National Training Project

Topical areas in the field have enhanced staff knowledge and competency in deafblind methodology. Even more successful and comprehensive has been the coordination of two "Mentor" projects. During the summer 1993, two deafblind certified Boston College graduates provided direct teacher-to-teacher instruction to newly hired classroom teachers. Each master teacher provided direct instruction, modeling and demonstrating to both the teacher and the parents. One master teacher actually lived with the family and was able to model behavior management techniques when situations arose.

The Project Coordinator participated on the Perkins National Training Project Consortium. Two summer graduate courses on deafblindness were provided nationally. Further, deafblind teacher competencies were developed and will be submitted as a standard to the Council of Exceptional Children for deafblind endorsement.

This activity addresses Objectives 3,4,7.

Impact

Two beginning teachers, two advanced level teachers and a parent were selected and sponsored to complete a deafblind communication course offered through the Perkins National Training Project in July 1995. The beginning teachers will be provided follow-up assistance on student action plans. The advanced "master" teachers will be provided follow-up assistance to both "mentor" the beginning teachers and to replicate the course in Missouri. A training module has been drafted for this purpose.

Direct application will be fostered through mentoring and professionals and parents will be invited to take the coursework in Missouri furthering local capacity building.

A second course on Integration will be attended by four people in July 1996.

8. Parent Training

An average of 50 parents participated in activities provided by the Project, each year, including "Family Enrichment Weekend" and home consultation. In addition, approximately 45 families participated in the MoSPIN home intervention project annually.

This activity addresses Objectives 1,3,8.

Impact

Families received information and competencies which heightened their confidence in dealing with their own child and with professionals.

9. Recruitment

There is a critical shortage of certified teachers in deafblindness in the Midwest. Efforts were made to recruit graduates from recognized universities which have deafblind endorsement/certification personnel-preparation programs.

This activity addresses Objectives 3,4,7.

Impact

Three Boston College graduates certified in deafblindness were recruited in 1993. One graduate took a permanent teacher position in a local public school in Kansas City and one in Arnold. The third did a practicum placement in the summer in Springfield. The Project Coordinator supervised the practicum student in Arnold prior to receiving full graduating status. Efforts like this continue to build local capacity in Missouri.

10. Materials/Resource Center

The Project provided packets, videos and texts for resource exchange. Information was also shared in the Project newsletter "FOCUS" (five times/year), MoSPIN newsletter (monthly) and the State newsletter "INNOVATIONS" (six times/year). New projects included a free loan system for BRAILLE N'SPEAKS, coordination with the American Printing House for the Blind Materials Center and Deafblind LINK.

Satellite technology was offered each year. MSB is a down-link site where professionals from across the State gathered to receive information from this medium. Topics included: Braille Literacy; Low Vision Assessment; Technology; Tactile Interpreting.

This activity addresses Objectives 3,4,7.

Impact

Up-to-date information on best practices is readily available and accessible and is cost-effective.

11. Census

The Deafblind Census and APH Registry mailings were consolidated.

This activity addresses Objective 7.

Impact

Five-hundred thirty-six (536) local school districts reported 193 deafblind children and 1072 legally blind children. Although there is no per student funding formula for deafblind, APH generates approximately $107 Quota funds for large type and braille materials per child registered. These funds are monitored under the supervision of the Project Coordinator.

12. Needs Assessment

The project collaborated a needs assessment process and subsequent data was included in the development of the CSPD plan to assure that the unique needs of individuals with deafblindness were addressed. Needs were determined by four needs assessment processes and priorities were set for the Deafblind Project:

I. Missouri Summit on Sensory Impairment, October 1994. Fifty professionals in the field, serving sensory impaired individuals Statewide, met for two days and identified the following priorities:

1. Training for professionals, paraprofessionals and parents.
2. Funding.
3. Networking/partnering/information sharing.
4. Regionalized services
5. Family support.
6. Research and empirical data.

These priorities drove the service delivery plan of the Project. The Program Coordinator participated on a Summit Steering Committee which met January and April 1995 and developed a subsequent strategic plan for service delivery to blind and deafblind children. An Executive Summary of a Statewide plan was drafted and will be presented to the Assistant Commissioner of the Missouri Department of Elementary and Secondary Education.

II. Customer/Consumer Needs Survey, September 1994. The results of a needs survey sent to 186 families and over 100 service providers indicated extremely high satisfaction regarding services received from the Project. The following priority content areas were identified as highly needed for future training:

1.	Communication/signing	32%
2.	Adaptive technology	21%
3.	Personal futures planning	18%
4.	Transition	18%

The Project objectives were consistent with needs identified by customers (families, consumers and providers).

III. Personnel Preparation Survey, September 1994. A survey sent to 150 certified professionals in Missouri revealed a need for deafblind specific coursework to be included in the course offerings currently available in Missouri. Further, 21% of the respondents expressed an interest to take the course if offered. Lack of supervision and follow up was a major weakness noted in the current personnel preparation system, adversely impacting application of knowledge to the classroom. The Project's proposed train-the-trainer and mentor program is designed to target this need.

IV. Planning Meetings with CSPD, Part H, SSSH, Task Forces and Deafblind Advisory Board. Meetings held with the stake holders revealed the need for continued interagency collaboration and local capacity building.

Training and technical assistance were among the primary objectives of the Deafblind Project and were specifically described in the project activity's design. Project training activities directly corresponded to the CSPD priorities and were coordinated with the State CSPD Coordinator who is on both the Deafblind Advisory Committee and the Missouri State Task Force for Persons with

Deafblindness. Training activities included: programs including effective practices and technology for low incidence groups, early childhood and parent training programs; programs on transition and personal futures planning; interagency collaboration and team building. Agreements were secured to provide graduate credit or CEUs for the INSITE train-the-trainer program, deafblind coursework in communication and inclusion and summer institutes. Follow-up assistance was provided through a mentor program. Technical assistance was provided Statewide to a variety of target audiences including families, early interventionists, educational and related service professionals, paraprofessionals and adult services providers.

Impact

The needs assessment data further supported Project scope for the Grant award of 1995-99 for services to deafblind children and youth.

VI. COMPONENT II

CURRICULUM SPECIALIST
MISSOURI DEAF-BLIND PROJECT

FINAL REPORT

OCTOBER 1, 1994 - SEPTEMBER 30, 1995

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Missouri Deaf-Blind Project Final Report
1994-1995

Introduction

The following final report is an update and summative accounting of the activities of component II of the Missouri Deaf-Blind Project from the period October 1, 1994 through September 20, 1995. It is intended to give quantitative and qualitative information about the two objectives of the Deaf-Blind Project in which the curriculum specialist share responsibility with other project staff.

Project Activities

Objective 3: To provide technical assistance to families and to public, private and state agencies on basic skills, sensory training, technology, best practices, transitioning, family dynamics and respite care orientation.

This objective has been addressed through local task force training provided through the Helen Keller National Center-Technical Assistance Center. The second and third local task force training workshops were held during this fiscal year on April 5-6, in St. Louis and September 13-14, 1995 in Kansas City. The purposes of these training sessions have been:

1. to provide specific skill building in topics related to deaf-blindness that have been identified by the local task force members themselves;
2. to provide communication and team building skills to assist the local task force members to establish and maintain effective teams; and
3. to provide a forum for networking among the different task forces to build their capacity to rely on others throughout the state who work through similar system issues to provide services for persons with deaf-blindness who are going through life transitions.

There have been several outcomes of these local task force training sessions. First it became obvious that the local task force members did not understand the entire model which had been established in which the state task force, the local task forces and the individual student IEP teams were to function. This lack of understanding of the "big picture" created a lack of communication between the local and state task forces. This issue was addressed in the third local task force training and in articles in the FOCUS newsletter. Secondly the local task forces took time during the year to take stock of where they have come as a group and what is working and what is not. This exercise gave valuable information to the State Task Force when organizing the team training and it also gave the local task forces an opportunity to celebrate their accomplishments. The local task forces have made a difference in the lives of individuals with deaf-blindness who they serve, yet it is often difficult to realize that success and the growth within the Task Force when members are diligently working to address local issues. Finally, it is the general consensus among all participants of the local task force training that opportunities for training and networking need to continue in the future. It will be a challenge for the local task forces and the State Task Force to pool resources and talents to bring all participants together in the future to continue their growth and the perpetuation of the model in Missouri.

Objective 4: To provide information assistance to families, SEAs and LEAs on basic skills, sensory training, technology, best practices, transitioning, family dynamics and respite care orientation.

Four issues of the *FOCUS on Children with Deaf/Blindness* newsletter have been published during this report period. The lead article for this years issues have been devoted to an overview of the Missouri model and highlighting each local task force. Two hundred eighty seven parents, educators and agency personnel receive this newsletter.

A resource handbook for parents, *The Future is Around the Corner! A Parent Handbook for Successful Transition* was published during this reporting period. This handbook was the collaborative effort of Deaf-Blind Grant staff and a number of parents and agency reviewers. One hundred copies of this handbook were published and disseminated with Deaf-Blind Grant funds. This handbook has been extremely well received by readers and requests for copies continue to come to the Center for Innovations in Special Education. This handbook has been entered into the collection of the CISE Loan Library, #1307 and may be borrowed and returned by parents and educators free of charge. Future plans are to republish the handbook to meet the needs of those requesting this resource.

The Curriculum Consultant is a standing member of the State Task Force and attends each meeting. Opportunities for training that take place around the state are communicated directly with the State Task Force and to the local task forces through the Focus newsletter.

Future Direction of Project

1. To improve the FOCUS newsletter, a mechanism will be established and timelines published to solicit articles from the members of the State and Local Task Forces. This will be done in an effort to make the newsletter a part of the model versus a publication that stands alone outside the model. It would be an improvement to have a standing article entitled "Issues/Solutions from the Field" to reinforce the communication among the local task forces.

2. The State Task Force should collaborate resources and personnel to continue the local task force training. The momentum and connections made to this point need to continue. Also there will always be turn over in personnel at the local levels who will benefit from training and support from the state and local task forces.

3. The State Task Force must take a leadership role in evaluating and improving communication with the local task force membership. This should be an ongoing process. A formalized communication mechanism should be established and continuous evaluated to improve communication between the local task forces and the State Task Force to enable the State Task Force to support the changes in system challenges faced at the local level.

APPENDICES

Component II
Curriculum Specialist Missouri Deafblind Project

Appendix A

Missouri Deafblind Statewide Newsletter: *FOCUS*

FOCUS

on Missouri Children and Youth
with Deaf/Blindness

October 1994

Missouri's Approach to Achieve Person-Centered Outcomes: A Partnership of State, Local and Individual Teams

Introduction

Missouri has had a long history of providing services to children and youth with deaf/blindness. The services and support provided to children with deaf/blindness, their families and those who provide direct instruction and therapy services has changed over the years. This article, and subsequent articles of the Focus newsletter, will describe in detail the existing model for serving Missouri's children and youth with deaf/blindness.

Missouri's Model - An Overview

Missouri, with the assistance of Helen Keller National Center - Technical Assistance Center, has adopted a model that is designed to build state and local capacity to provide appropriate services for children and youth with deaf/blindness. It is a known fact that adult outcomes for students with deaf/blindness are very poor. The Individual's with Disabilities Education Act (IDEA) of 1990, now requires that transition services be addressed in the Individualized Education Program (IEP) for each special education student, 16 years-of-age and older. Yet many individual student IEP teams cannot plan and provide transition services alone! To support the transition plans developed by IEP teams, Missouri has adopted a multi-level interagency approach (see Figure 1, Page 2). The multi-level interagency model is made up of IEP teams, three local interagency task forces, and the State Missouri Interagency Task Force for Persons with Deaf/ Blindness.

IEP Teams

The foundation for the Missouri model is the individualized education program planning teams who meet at least annually to plan special education and related services for each student. IEP teams for students who are 16 years-of-age and older are also concerned with the future adult services and supports a student will need. IEP teams use each student's unique transition needs, preferences and interests to decide classroom instruction and community experiences needed to develop employment and other post-school adult living objectives. Some students with deaf/blindness go through Personal Futures Planning to develop a vision of possibilities for their future. The information gathered during the personal futures planning process is valuable to the IEP team's transition planning. It is not uncommon for IEP teams to come up against obstacles and barriers to appropriate community services for individuals who are ready to exit school.

Local Task Forces

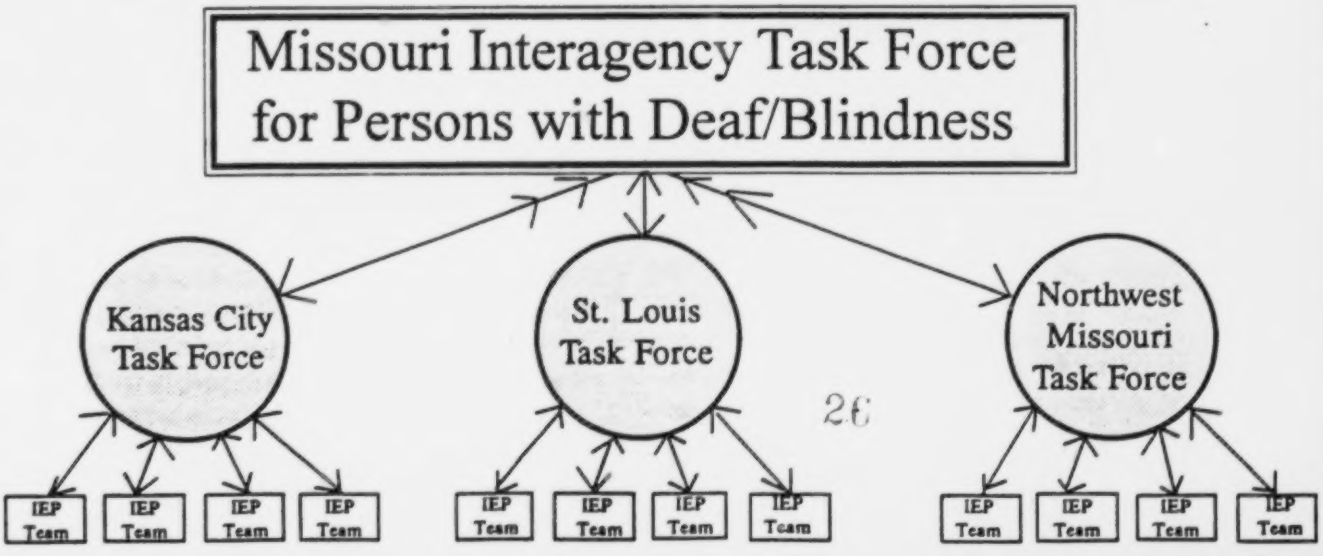
To address barriers to appropriate services for youth with deaf/blindness in their community, three local task forces have been formed in Missouri. The St. Louis Task Force was formed in 1992, the Kansas City/Blue Springs Task Force started in 1993 and the Northwest Missouri Task Force began in early 1994. These local task forces are made up of adults with deaf/blindness, parents, school personnel, local representatives of state agencies and adult services providers. Each Missouri local task force has spent time getting to know each members role in providing services to people with deaf/ blindness. Each local task force is responsible for becoming knowledgeable about local services and funding resources. Each local task force must also determine the transition service gaps in their local community and to form local partnerships to address those service gaps. Local teams can also assist IEP teams in securing the local resources needed to insure a successful transition from school to adult life. Local task forces identify transition issues, services and needs; pool resources; and share information to ensure quality transition services are in place in the community. Finally each task force is a link between the Missouri Interagency Task Force and the IEP teams. Just as the local task force serves as a resource to IEP teams, each local task force sends a representative to the state task force to communicate issues that cannot be resolved at the local level.

Missouri Interagency Task Force

The Missouri Interagency Task Force has been in existence since 1989 and was formed to improve state-wide services for individuals with deaf/blindness through policy and regulation changes. Members of the state task force include parents, educators, local task force representatives, state agency representatives and staff of the Missouri Deaf/Blind Project. The state task force has changed its focus from addressing the issues and needs of individual youth with deaf/blindness to being a support for the local task forces. Each local task force representative to the state interagency task force reports progress and barriers at the local level to the state interagency task force. The state task force then provides recommendations and suggestions to the local task force representatives to take back to their local communities. Frequently the state task force can recommend creative funding solutions and contacts in the local community who can be instrumental in creating changes in the way services are delivered. This process of informing the state task force of local issues enables the state task force to identify and change agency regulations that impede transition and community participation for people with deaf/blindness throughout Missouri. This connection between the state and local teams is crucial for addressing the barriers to achieving meaningful adult life styles. Regular communication with the local teams is imperative. The state interagency task force has also provided training and networking opportunities for the collective state and local task forces.

To address the needs of children with deaf/blindness and their families who do not live in St. Louis, Kansas City or Region 1 in northwest Missouri, the Missouri Interagency Task Force has engaged in discussions with existing state interagency teams that address the needs of children and youth with disabilities. The state task force is exploring ways to tap these established multi-level interagency councils to help meet the needs of children with deaf-blindness in other Missouri locales.

Missouri's Model to Achieve Person-Centered Outcomes: A Partnership of State, Local and Individual Teams



(Figure 1)

The Missouri Interagency Task Force has also developed a *Deaf/Blind Service/Resource Directory* that lists governmental agencies, private service delivery organizations, advocacy groups and community resources. This directory is available by calling Vicki at Missouri School for the Blind Outreach Services at (314) 776-4320, ext. 251.

Conclusion

The goal of the Missouri model is to have all young people with deaf/blindness leave school with the skills, supports and services needed to achieve quality, integrated adult lifestyles. The partnership among IEP teams, local task forces, and the Missouri Interagency Task Force keeps the dialogue going to address issues and potential solutions to achieve person-centered adult outcomes for Missouri's citizens with deaf/blindness.

Parent to Parent

PARENT TO PARENT is committed to assisting parents of children with visual impairments, including those children with additional disabilities.

Our goal is to offer support from parents who have learned to cope with the challenges of raising a child with visual impairments. We are parents, not therapists or doctors. We have been trained to listen and share information about our experiences and knowledge of available resources. Whenever possible, a parent will be matched with another parent whose child has a similar diagnosis. Information shared will be held in strict confidence.

Parent to Parent Offers

- Emotional support for parents when they learn their child has a visual impairment
- Current information on visual impairments and other disabilities
- Information on community resources
- Parent meetings and social events
- Training for parents who would like to become volunteer Support Parents

For more information call (314) 776-6351

1992 National Symposium on Children and Youth Who Are Deaf/Blind

The proceedings from the 1992 National Symposium on Children and Youth Who Are Deaf/Blind is now available from Teaching Publications.

This three day symposium, supported by the U.S. Department of Education, identified critical issues, effective practices, and future directions in the provision of educational and related services to children and youth (birth to 21 years) who are deaf/blind.

The 240 page book presents the full texts of 20 invited papers and lists recommendations proposed by symposium focus groups covering a wide range of contemporary issues.

The symposium's novel structure is discussed, along with planning, interpreting, and making the conference accessible.

To order your copy send a check or money order to:
1992 Symposium Proceedings
Teaching Research Publications
345 N. Monmouth Avenue
Monmouth, OR 97361
or call: (503) 838-8792
FAX: (503) 838-8150
TTY: (503) 838-8821

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Focus on Missouri Children and Youth with Deaf/Blindness is published by the Center for Innovations in Special Education, University of Missouri-Columbia. Funding for this newsletter is through the Missouri Deaf/Blind Project and Missouri Department of Elementary and Secondary Education, Division of Special Education. If you have special needs as addressed by the Americans with Disabilities Act and need this publication in an alternate format, efforts will be made to meet your needs. For further information, contact Linda Bradley at the Center for Innovations in Special Education, 401 E. Stewart Road, Columbia, MO 65211, (800) 392-0533 or Linda Van Niedringhaus, Missouri School for the Blind, 3815 Magnolia Ave., St Louis, MO 63110.

CISE

Center for Innovations in Special Education

The former Missouri LINC and Special Education Dissemination Center, funded by the Missouri Department of Elementary and Secondary Education, are excited to serve you through the new Center for Innovations in Special Education. The mission of the Center is to expand opportunities and improve outcomes for students with disabilities. Staff are committed to providing high quality services and materials to support those striving to help these learners achieve their potential.

The new Center offers the following services:

- **Conferences**
  - *Special Education Administrators
  - *Partnerships for Transition--(formerly VAC/VRC)
  - *Innovations in Special Education
  - *Missouri PARAdise
- **Summer Institutes**
  - *Credit courses offered at the University of Missouri-Columbia
- **Effective Practices/Model Programs Project**
  - *Identification and dissemination of information about exemplary special education practices/programs
- **Loan Package Program**
  - *More than 1,100 materials available for short-term loan
- **Modules, fact/resource sheets**
  - *Free printed materials that address specific topics
- **Newsletters/Publications**
  - *Missouri *Innovations in Special Education*--four issues per year for special educators
  - **PARAdise News*--two issues per year for special education paraprofessionals
  - **Transition LINC*--biannual topical monograph for vocational and special educators
  - **Focus*--a newsletter for Missouri children and youth with deaf/blindness
  - *Print Materials--variety of materials distributed free or at minimal cost through the Instructional Materials Laboratory
- **Information Requests**
  - *Responses to requests for topical information
- **Deaf/Blind Support Services**
  - *Consultation and a bimonthly newsletter for parents and educators

Loan package requests	- (800) 729-7332 (MO only)
Other requests	- (800) 392-0533 (MO only)
General information	- (314) 882-2733 or - (314) 882-3594

401 East Stewart Road, Columbia, MO 65211

Expanded Office Hours:
7:00 a.m. - 5:00 p.m. - Monday - Friday

Center for Innovations in Special Education
401 East Stewart Road
Columbia, MO 65211

Address Correction Requested

Attention: Parents of Children with Deaf/Blindness

FOCUS

on Missouri Children and Youth with Deaf/Blindness

December, 1994

WHAT'S HAPPENING IN THE STATE?

by Larry Rhodes, Missouri School for the Blind

The October issue of *FOCUS* described the approach Missouri is taking to achieve person-centered planning and identify and address barriers to improve services provided to deaf/blind individuals and their families. This approach involves a partnership of an individual's direct service team with local and state teams (called task forces). To begin to describe this model in detail, this issue of *FOCUS* will describe the purpose and function of the State Deaf/Blind Task Force.

Missouri Interagency Task Force for Persons Who Are Deaf/Blind (a.k.a. "State Deaf/Blind Task Force")

Prior to 1989, deaf/blind adults, families of deaf/blind individuals, educators of deaf/blind students, other agencies and institutions providing direct and indirect services to deaf/blind individuals and their families, and many other interested individuals and groups throughout the state of Missouri, as well as the entire country, experienced problems in securing appropriate services for deaf/blind individuals and their families. Two major areas of activity where these individuals and groups often felt they were working in isolation while trying to solve these problems was in the area of transition from school into adulthood and in the area of transition from a residential education/habilitation facility back into the deaf/blind individual's home community.

In 1989, a group of Missouri parents, educators, and adult service providers met and formed a task force to specifically address the program and service delivery issues facing deaf/blind individuals and their families. In 1990, a core group of individuals from the task force, along with members of task forces from other states, received extensive training on how to become an effective task force from the Helen Keller National Center-Technical Assistance Center. This task force eventually became known as the Missouri Interagency Task Force for Persons Who Are Deaf/Blind. It is unofficially called the "State Deaf/Blind Task Force." The State Task Force has met bimonthly in central Missouri.

For the first few years, the State Deaf/Blind Task Force focused on addressing the issues and needs of specific deaf/blind youth and younger adults. During this time period, the State Deaf/Blind Task Force identified the nature or cause of some of these issues. Some of these issues were statewide in nature and, therefore, needed to be addressed on a state wide basis through collaboration of parents and statewide education and adult services agencies. Other issues were local and needed to be addressed through regional/local collaboration. Furthermore, the majority of both statewide and local issues were found to be systems issues.

Since the State Deaf/Blind Task Force was primarily addressing the issues and needs of deaf/blind individuals from the metropolitan St. Louis area and since a significant number of the problems faced were local systems issues, the State Deaf/Blind Task Force created a sub-committee that met in St. Louis. Making it more accessible to involved education and adult service agencies providing services to the affected deaf/blind individuals. This sub-committee eventually became the first of three independent "local deaf/blind task forces." (*The next issue of The Focus will spotlight the St. Louis Deaf/Blind Task Force*).

The State Deaf/Blind Task Force has since shifted its focus from addressing the issues and needs of specific deaf/blind individuals to providing support for the local deaf/blind task forces and to identifying and addressing statewide system problems that affect services to deaf/blind individuals. The State Deaf/Blind Task Force supports the local deaf/blind task forces by: providing organizational support to new local task forces, providing training and networking opportunities, and supporting the local task forces in implementing their action plans. The State Deaf/Blind Task Force improves services for deaf/blind individuals by collecting data, information, and outcomes from the local task forces and then using this information to make recommendations regarding policy and/or regulation changes at the state level.

Along with ongoing identification of statewide systems problems, the State Deaf/Blind Task Force is coordinating three major projects that will assist the local task forces.

The first major project is coordinating a three part special training for members of the three existing local deaf/blind task forces. The purpose of this training is to provide information to members to these local deaf/blind task forces regarding deaf/blindness, interagency collaboration, team building/problem solving, and other topics selected by the local deaf/blind task forces. This training is being conducted by the Helen Keller National Center-Technical Assistance Center. The first part of the training was held in September, 1994 at the Lake of the Ozarks. The next part of the training will be held in April of 1995, in St. Louis. The third and final part of the training will be held in September, 1995 in Kansas City.

The second major project involves coordinating consumer specific technical assistance to the direct service staff of education and adult service agencies who are providing services to selected deaf/blind transition age youth.

This technical assistance is also being provided by the Helen Keller National Center-National Technical Assistance Center. In 1993 and 1994, this technical assistance was provided to organizations and agencies participating on the St. Louis Deaf/Blind Task Force. In 1995, this technical assistance will be provided to organizations and agencies participating on the Greater Kansas City and Region 1/St. Joseph Deaf/Blind Task Forces.

The third major project involves the possible development of a series of training modules on deaf/blindness to be used for training education and adult service agency staff.

The State Deaf/Blind Task Force currently consists of individuals representing the following groups and agencies: consumers, parents, Bureau of Deaf Services, Department of Elementary and Secondary Education, Department of Mental Health - Regional Centers, Missouri 307.11 (Deaf/Blind) Project, Missouri School for the Blind, Missouri School for the Deaf, Rehabilitation Services for the Blind, and State Schools for the Severely Handicapped. State Task Force members representing adult service agencies are individuals who: can effect policy changes, can effect new procedures, can effect licensure and certification changes, and whose agencies that primarily serve this population on a statewide basis.

SUMMARY

The State Deaf/Blind Task Force has evolved while the entire system of services for deaf/blind individuals was changing in Missouri. Currently the State Deaf/Blind Task Force provides support to three local task forces while also tackling state-wide system issues. To further clarify the approach Missouri is taking to achieve person-centered planning, the next issue of *FOCUS* will describe the activities of the St. Louis Task Force.

Upcoming Learning Opportunities

VIISA Training

VIISA training for two graduate credits from Lindenwood College will be held on March 3 & 4 and May 19 & 20, 1995. Students will be required to complete eight (8) home study assignments. The target audience is early interventionists who serve children birth through five years whose primary handicapping condition is vision impairment/birth. The instructor will be Ann Rutherford, Children's Center for the Visually Impaired of Kansas City. For more information contact:
Linda Van Eck Neidringhaus
Missouri School for the Blind
(800) 622-5672

Weekend with the Experts and Parents Learning Vacation

The Missouri School for the Blind will offer a learning weekend for parents and professionals on July 29 and 30, 1995. Dr. Mary Morse of the Longitudinal Project in New Hampshire will present on Cortical Vision Impairment. This workshop is designed for all professionals who work with students who are blind, visually impaired or deaf-blind. There is no charge for this workshop and housing and meals at the School for the Blind are also free. Parents are also invited to the Missouri School for the Blind on July 29 and 30 for a Parents Learning Vacation. For more information on both of these learning opportunities contact: Jacqui Grable, Missouri School for the Blind, (800) 622-5672

Missouri PARAdise, Special Education Paraprofessional Conference

"PARAS OPEN DOORS"

When: Monday, April 3, 1995

Where: Holiday Inn Executive Center, 2200 1-70 Drive S.W., Columbia, MO 65203; (314) 445-8531 or (800) 465-4329; fax (314) 445-7607

What: Join us in Columbia for the eighth annual statewide conference for paraprofessionals who work with students with disabilities in Missouri schools. The conference will include a keynote address by former **Miss America, Dr. Debbye Turner**, concurrent sessions, a video theater, exhibits, and more. Take advantage of this opportunity to hear from experts on a variety of topics and issues related to your job as a paraprofessional, as well as meet and share experiences with other paraprofessionals from across the state. **Participants will receive .6 CEUs (6 hours of training) for attending the entire converence.** Social security numbers must be submitted with registration form for University of Missouri record-keeping purposes.

Cost: Pre-registration fee is $28. Late registration will be $38 (after March 17, 1995) so register early. Refunds will not be made after March 17. Lunch, refreshments and handouts are included in the registration fee. **Travel and lodging will be the responsibility of the participant or his/her district.**

Hotel: Each person is responsible for his/her own hotel reservations.

Sponsers: Center for Innovations in Special Education (CISE), University of Missouri-Columbia; and Division of Special Education, Missouri Department of Elementary and Secondary Education (DESE).

For Registration Information Contact:
Kathy Kroll or Alice Schawo
Extension Conference Office
University of Missouri
348 Hearnes Center
Columbia, MO 65211
(314) 882-4038

For Program Information Contact:
Nancy Brock
Center for Innovations in Special Education
University of Missouri
Parkade Center, Suite 152
601 Business Loop 70 West
Columbia, MO 65211, (314) 882-0585

Letting Go

The bittersweet process of "letting go" allows for time to examine the fears which surround any life change. Our willingness to "let go" acknowledges our success as parents, recognizes the rights, abilities and potentials of our children, and sets the stage for future growth and independence.

1. "Letting go" is an individual issue. It's natural to have mixed feelings about our sons and daughters moving on. The feelings of joy and sorrow, fear and relief are familiar to all of us.
2. "Letting go" is an issue common to all of us. At those times when we encounter change in our lives, we experience a wide range of feelings. The issues can become more complex and personal when disabilities and/or chronic illness are involved.
3. "Letting go" is a logical outcomes of normalization. It is what we, as parents, have worked toward for years. In the days when our sons and daughters were educated in segregated sites and had fewer opportunities to participate in the larger community, "letting go" was perhaps easier than it is today.
4. "Letting go" is allowing our sons and daughters to achieve degrees of independence, which is, after all, every person's right. The freedom to have opportunities to increase knowledge and develop skills promotes the growth of personal competence and genuine self-esteem.
5. "Letting go" is a continuous process that occurs as our children grow and mature. Believing in our sons and daughters and being realistic about potential problems are important to the process. Being optimistic about finding solutions and about the future makes the process easier.

When it is time for our sons and daughters to move on, we have earned the right to rejoice in our accomplishments as parents and in the strengths and abilities of our children.

Source: PACER Center, Inc., (1991). 4824 Chicago Ave. S., Minneapolis, MN 5417-1055; (612) 827-2966.

Linda K. Bradley, Editor
Linda Van Eck Niedringhaus,
Missouri Deaf/Blind Project

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Columbia, MO 65211

Address Correction Requested

Attention: Parents of Children with Deaf/Blindness

June, 1995

FOCUS on Missouri Children and Youth with Deaf/Blindness

LOCAL INTERAGENCY TASK FORCES: WHERE THE ACTION IS!

The last issue of *FOCUS* described the history and role of the Missouri Interagency Task Force for Persons Who Are Deaf/Blind. This group soon learned that local service issues for individuals could not easily be addressed by a statewide task force. Each community in our state has different work and living opportunities which are best tapped by members of that community. Therefore, three local task forces have been formed to build the capacity of local parents and professionals to address the service needs of specific individuals with deaf/blindness in their community. This issue of the *FOCUS* newsletter will feature the activities of the "oldest" two local deaf/blind task forces in Missouri, St. Louis and Kansas City. Both task forces were established because a need for appropriate services for adults with deaf/blindness was evident.

St. Louis Interagency Task Force for Persons Who Are Deaf/Blind

The St. Louis Task Force was established in July, 1992 with three initial goals: (1) to identify and prioritize the transition age clients in St. Louis County, (2) identify the service needs and potential lead agencies, and (3) match the clients and agencies to best meet the needs of the clients. To help with the age old problem of "if you don't know where you're going, how will you know if you're there?", the task force developed a mission and belief statement. The mission of the St. Louis Deaf/Blind Task Force is to assist deaf/blind persons and their families in achieving full access to the community through collaboration.

The St. Louis Deaf/Blind Task Force holds certain fundamental beliefs regarding the rights of deaf/blind persons and their families:

- the right to a quality life reflecting dignity, self-respect, self-reliance, autonomy, and personal choice;
- the right to full participation in the mainstream of community life regardless of the severity of the disability; and
- the right to supports that embrace these values.

The St. Louis Deaf/Blind Task Force holds the fundamental belief that the needs of deaf/blind persons are unique and individualized.

The St. Louis Deaf/Blind Task Force holds the fundamental belief that community team work and collaboration enhances the delivery of services.

The following protocol was developed to define the membership and working procedures of the task force. Membership of the local task force will include individuals (consumers and/or their significant family members) as well as local service providers (both administrative and direct care), and local state agency representatives (both administrative and direct care) responsible for service delivery for persons with deaf/blindness. Each local task force will also include individuals who serve on the State Level Task Force.

1. The local task force will meet on a regular basis to address the service needs and related supports of persons who are deaf/blind within the St. Louis area.
2. Each local task force member (individual and agency) will have equal responsibilities on/for the local task force.
3. The local task force will routinely receive Helen Keller National Center action plans and individualized plans to facilitate service delivery.
4. The local task force will respond to individual consumer/family and agency issues and concerns through a problem solving process.
5. The local task force will help identify local-level service delivery and systems barriers.
6. The local task force will facilitate service delivery through the resolution of local-level barriers.
7. The local task force will communicate service delivery and systems issues to the State Interagency Task Force.
8. The local task force will assist in the development of local resources, and the dissemination of information to enhance local service delivery.

9. The local task force will assist in the identification of local in-service training needs and will communicate available training opportunities to the group.
10. The local task force will work in partnership to identify and provide training and skill building opportunities to enhance the available services in the community.

In addition to the work done to organize the task force, specific activities were initiated to meet local needs. One priority need identified was the need for training of staff to work with people with deaf/blindness. To accomplish this overwhelming task, the St. Louis "S.W.A.T. Team" was formed. To build local capacity and local interagency collaboration, several adult service agencies that are participants of the St. Louis Local Deaf/Blind Task Force have formed a core team of professionals who have received extensive training in providing services to deaf/blind consumers. At least one professional from most of the agencies that participate on the local task force serves on the S.W.A.T. Team. The purpose of the S.W.A.T. Team is to locally build a base of expertise in providing services to deaf/blind consumers in the areas of supported living and supported employment. The S.W.A.T. Team receives ongoing training from the Missouri Deaf/Blind Project, the Bureau of Deaf Services, Helen Keller National Center (HKNC) National Training Team and the HKNC Technical Assistance Center.

A spin-off of the local S.W.A.T. Team is the formation and training of a core team of staff from two adult service agencies, St. Louis Association for Retarded Citizens (SLARC) and Bellefontaine Habilitation Center. These core teams receive training and, in turn, provide initial technical assistance to staff within their agency. One unique training technique that is taking place at Bellefontaine is "Sign of the Day." Each day posters of a new sign are displayed and staff are encouraged to use that sign to increase their vocabulary.

Collaborative efforts among members of the St. Louis Task Force for Persons Who Are Deaf/Blind have also produced positive results for several individuals with deaf/blindness. People have moved from the large congregate setting to group homes. Individuals have increased their work stamina to six hours per day and have moved from sheltered work experiences to employment in the community.

To contact the St. Louis Deaf/Blind Task Force for assistance or information, please contact: Susan Bonner, St. Louis Regional Center, 211 North Lindbergh Blvd., St. Louis, MO 63141, 314-340-6563.

Greater Kansas City Task Force

In November 1993, fourteen interested school and adult service agency people met to discuss the transition needs of deaf/blind students in the metropolitan Kansas City/Independence area. This meeting led to the establishment of the second local Deaf/Blind Task Force in Missouri, the Greater Kansas City Deaf/Blind Task Force. Like the St. Louis Deaf/Blind Task Force, the Kansas City Task Force spent much time at its first few meetings developing belief and mission statements. The Task Force also defined its membership at that time.

The belief statement of the Greater Kansas City Deaf/Blind Task Force says that it holds certain fundamental beliefs regarding deaf/blind individuals and their families:

- the right to a quality of life reflecting dignity, self-respect, self-reliance, autonomy, and personal choice;
- the right to full participation in the mainstream of community life; and
- the right to supports that embrace these values.

The Greater Kansas City Deaf/Blind Task Force believes that the combination of visual and auditory impairments creates unique needs for deaf/blind individuals, affecting their relationship with their community and environment.

The Greater Kansas City Deaf/Blind Task Force believes that our vision creates our future.

The Greater Kansas City Deaf/Blind Task Force believes that through persistent, patient community collaboration, the deaf/blind individuals can be better embraced by the community as a whole.

From this belief statement the following mission statement was created:

The mission of the Greater Kansas City Deaf/Blind Task Force is to assist deaf/blind persons and their families in achieving full access to the community through collaboration.

During those first few meetings, the Task Force also identified to whom it would provide support:

1. any deaf/blind consumer - regardless of age - (and the consumer's family) going through transition;
2. any deaf/blind consumer - regardless of age - (and the consumer's family) experiencing problems in receiving appropriate and adequate services (education, habilitation, housing, transportation, etc.); and
3. any agency (education, adult service, community, etc.) providing services to deaf/blind consumers and their families.

The Greater Kansas City Deaf/Blind Task Force was the first Task Force in the state to clearly assert that it would address the needs of *all* deaf/blind consumers of any age and their families in the Greater Kansas City Area. The Task Force decided to limit its service area at this time to the counties of Platte, Clay, and Jackson in western Missouri. This does not mean that the Task Force will not act as a resource to individuals and agencies outside that three county area.

Membership in the Greater Kansas City Deaf/Blind Task Force includes the parents of three deaf/blind consumers and representatives from the following agencies: Alpha Point, Blind Focus, Special Services Center at Blue Springs Schools, Bureau of Deaf Services, Children's Center for the Visually Impaired, Developing Potential, The Great Plains Regional Office of the Helen Keller National Center, ICAN, Deaf/Blind Program of the Kansas City (Missouri) Schools, Kansas City Regional Center, Missouri 307.11 (deaf/blind) Project, MPACT, State Schools for the Severely Handicapped, UMKC--University Affiliated Program, and Whole Person.

For the Task Force to better identify and address service issues of deaf/blind consumers and their families, the Task Force has created several committees. These committees are:

1. The Personal Futures Planning (PFP) Training Committee - to coordinate a series of facilitator trainings in the Personal Futures Planning process.
2. The Funding Committee - this committee was first established to find funding for the Personal Futures Planning Training. Now this Committee will secure funding for various projects and activities conducted by the Task Force.
3. The Mission-Statement-Values-Statement-Protocol Committee - to develop the Task Force's mission statement, values statement, and protocol and to review these documents on a yearly basis.
4. The Training Committee - to periodically assess the training needs of the Task Force and to coordinate training to address those needs.

The Greater Kansas City Deaf/Blind Task Force has achieved several accomplishments in the short time it has been in existence. These accomplishments include training five individuals who are now facilitators in the Personal Futures Planning process. Over the past few months it has pursued and secured funding for training these five individuals. The Task Force has also been increasing an internal awareness of resources/services available to deaf/blind consumers and their families through "Show and Tell" activities during each Task Force meeting. The Task Force has joined an organization called Disabilities Employment and Awareness Network (DEAN), a nonprofit organization composed of individuals, agencies, and employers concerned with the employment of persons with disabilities in the Kansas City area. Agencies participating on the Kansas City Task Force have been receiving technical assistance from the Helen Keller National Center--Technical Assistance Center for specific deaf/blind consumers. A census of deaf/blind consumers in the metropolitan Kansas City/Independence area is being initiated by the Task Force. For the past ten months, The Task Force has been participating in the Local Deaf/Blind Task Force Training being conducted by the Helen Keller National Center--Technical Assistance Center.

If you are interested in contacting the Greater Kansas City Deaf/Blind Task Force for assistance and/or information, please contact: Diane Odegard, Chairperson, c/o Deaf/Blind Program, Phillis Wheatley School, 2415 Agnes, Kansas City, MO 64127, 816-871-6887; or Nancy Martin, Secretary, c/o Special Services Center, Blue Springs School, 2103 West Vesper, Blue Springs, MO 64015, 816-224-1360.

Conclusion

The local Task Forces in St. Louis and Kansas City have worked diligently to improve community services for deaf/blind consumers and their families. By learning about the services represented on their respective Task Force and using the collective energy and resources, each Task Force has had a positive impact on the lives of deaf/blind consumers. Interagency collaboration is not an easy task, there are no "rules" to follow to ensure success and it takes a lot of time and patience! Yet both Task Forces demonstrated that improved quality of life for deaf/blind consumers and their families is the reward for their work.

* * *

For those who like peace and quiet…
a phoneless cord.

TRAINING OPPORTUNITIES

Missouri School for the Blind Summer Training Schedule

Weekend with the Experts on "Cortical Vision Impairment," presented by Dr. Mary Morris from Vermont is July 29-30. That same weekend is the Family Learning Vacation on "Parent Advocacy." For further information, contact Jacqui Grable at 314-776-4320, ext. 114.

University of Missouri, Center for Innovations in Special Education Summer Courses

The Center for Innovations in Special Education (formerly Missouri LINC and Special Education Dissemination Center) offers these courses through the University of Missouri during the Summer, 1995 semester:

- L/F372 Methods in Vocational Education for Students with Disabilities and Disadvantages; June 12-16, 1995, 1-5 p.m. General, special, and vocational educators who teach students with disabilities or disadvantages will be presented current information on the following topics: Challenges to Educators in the 90s, Student Assessment, Learning Styles, Transition: IDEA and School-to-Work Opportunities, Tech Prep, Instructional Strategies, Work Place Accommodations, and Real Work Experiences. CISE staff, along with guest lecturers, will provide the instruction.
- L360-1 Leadership in Transition; June 19-23, 1995, 1-5 p.m. This institute will focus on developing leadership skills that will assist educators in improving the transition of students with disabilities from school to adult life. Students will be required to conduct a needs assessment, develop and implement a program improvement plan, and demonstrate change in their district's implementation of transition services for students with disabilities. This institute spans the 1995 summer session and the 1995-96 academic years.
- L410-4 Seminar: Environmental Adaptations for Inclusive Classrooms: Meeting the Needs for Behaviorally Challenged Students; July 10-14, 1995, 1-5 p.m. This course is designed to provide educators with strategies for adapting classroom environments and adapting classroom practices to better meet the needs of all students. Specific areas of discussion will include the establishment of a philosophical focus, the development of appropriate expectations, behavioral change and assessments, and the shared responsibility of educating children.

For information about any of the courses offered through the Center for Innovations in Special Education, contact Charlotte Azdell at 800-976-2473 or 314-884-7275.

University of Northern Colorado Graduate Tuition Assistance Available

Graduate assistanceships are available for students pursuing Masters degrees or licensure in special education with emphasis in visual impairments. Students will be prepared to work with infants, toddlers, children, and youth who are blind or visually impaired. The program has been enhanced with a new multicultural focus in which graduates will be prepared to teach students from different cultural backgrounds, including those who use English as a second language.

Applications are welcome from all persons and are particularly encouraged from members of minority groups and those who are bilingual. For more information, contact Prof. Madeline Milian-Perrone, Coordinator, at 303-351-1683 or Prof. Kay Alicyn Ferrell at 303-351-1653, University of Northern Colorado, Division of Special Education, Greeley, CO 80639.

Lilli Nielsen National Conference Novi, Michigan

The Blind Children's Fund will host "Active Learning: Turning Latent Potential into Dynamic Ability for Infant, Preschool and Multi-Impaired Blind and Visually Impaired Children." The presenter is the noted Danish educator, Lilli Nielsen, Ph.D. This is a one week introductory course presenting Dr. Nielsen's Activity Learning Approach. It will be held in Novi, Michigan, June 19-23, 1995. Original and creative new techniques and materials will be introduced for effectively providing new learning environments for blind, visually impaired, and multi-impaired children. The target audience is parents, educators, and therapists. For further information or to register call 517-333-1725 or 810-540-4678, or write to the Blind Children's Fund, 2875 Northwind Drive, Ste. 211, East Lansing, MI 48823-5040.

Minnesota Summer Institute on Deaf/Blindness

The Minnesota Department of Education and the Minnesota Deaf/Blind Technical Assistance Project are conducting the sixth Summer Institute on Deaf/Blindness, June 27-29, 1995. This summer institute is designed to enhance the skills of professionals in identifying and working with individuals with deaf/blindness. Speakers include Jeanne Prickett from the Mississippi School for the Blind who will present "Curriculum about Communication and Orientation and Mobility"; John Walters, Helen Keller National Center on "Behavioral Management"; and Deaf/Blind Consumers Panel. The conference will be held at St. John's University, Collegeville, MN. Conference registration is $90.00 that includes meals and lodging (based on double occupancy room) and $30.00 for a one-day session, including lunch. For more information, call 612-779-5837 or 800-848-4905 or the Minnesota Deaf/Blind Technical Assistance Project, 201 Capitol View Center, 70 West County Road B-2, Little Canada, MN 55117.

PARENT/GUARDIAN TRANSITION QUESTIONNAIRE
A GUIDE FOR TRANSITION PLANNING

Your thoughts to these questions will assist you and the IEP team to develop transition goals and objectives in your child's IEP.

1. Has the school personnel talked with you about the post-school future of your son/daughter?

2. What do you want for your son/daughter during the next year, in 5 years, 10 years?

   Recreation/Leisure:

   Vocational:

   Community:

   Domestic:

3. What most concerns you about the future of your son/daughter?

4. When your son/daughter made a transition in the past (e.g., from one school to another), what were the problems encountered, if any?

5. Are you presently in contact with any agencies that will or may be involved with your son/daughter after graduation?

6. Are you aware of any community agencies that will or might be involved with your son/daughter? Do you plan on making or maintaining contact with them?

7. What do you anticipate to be your level of involvement with your son/daughter upon graduation from high school? Is this acceptable to you?

8. With whom and where would you like your son/daughter to live? Specify the nature of the living situation (e.g., apartment, house, etc.).

9. Where would you like your son/daughter to work? Specify the nature of the work.

10. What recreation/leisure facilities has your son/daughter utilized? Which one would you like him/her to use upon graduation from high school?

Source: Midwest Regional Resource Center (1982). *Child-parent-educator: The link to success.* Des Moines, IA: Drake University.

HELEN KELLER SPEAKS TO MILLIONS THROUGH MISS AMERICA

Share Helen Keller's vision by participating with agencies, schools, organizations, and businesses worldwide in the **Helen Keller National Center's (HKNC) 1995 Deaf/Blind Awareness Campaign.** This year Heather Whitestone became the first Miss America with a disability. Miss Whitestone is profoundly deaf, but reminds us that nothing can prevent the realization of a dream. It was Helen Keller who had inspired her to "know your problems, but don't let them master you." Now, like her role model, Miss America's message of "face your obstacles, work hard, and build a support team" inspires **all** people. This is an especially relevant message for people with deaf/blindness.

Originally proclaimed by Congressional resolutions and Presidential signatures in 1984 and 1985, awareness activities and events featuring information about significant vision AND hearing loss or deaf/blindness now occur throughout the year, beginning in June, the month of Helen Keller's birth date.

All citizens, health organizations, civic groups, libraries, schools, and agencies are encouraged to plan state and local activities during the month of June, and especially during the week of June 25-July 1. A sample proclamation, a radio public service script, list of suggested activities, 1995 poster, ad slicks, and this press release are available at no cost from the Public Relations Department, Helen Keller National Center, 111 Middle Neck Road, Sands Point, NY 11050, or by calling 516-944-8900, ext. 325 (voice), 516-944-8637 (TTY).

The HKNC is the ONLY national program which provides diagnostic evaluation, short-term comprehensive rehabilitation and personal adjustment training, and job preparation and placement for ALL Americans who are deaf/blind. Local services and training are offered nationwide to these individuals, their parents, and professionals in the field through HKNC's ten regional offices, some 40 affiliated agencies, a National Training Team, Technical Assistance Center, Services for Older Adults, and a National Family Association for Deaf/Blind which the Center partially supports.

If you know someone who is deaf/blind, or work with someone who could benefit from programs and specific services that build self-reliance and independence through dedicated support teams, please call the Helen Keller National Center at 800-255-0411, ext. 275.

Linda K. Bradley, Editor
Linda Van Eck Niedringhaus, Director
Missouri Deaf/Blind Project

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Attention: Parents of Children with Deaf/Blindness

September 1995

FOCUS on Missouri Children and Youth with Deaf/Blindness

SAINT JOSEPH/REGION 1 DEAF-BLIND TASK FORCE

This is the final article in a series of articles appearing in *Focus* regarding the Missouri Deaf/Blind Task Force Model and the four existing task forces in the state of Missouri based upon that model.

In December of 1993, Vivian Hays contacted two members of the Missouri 307.11 (Deaf/Blind) Project. She was very concerned about the future of her son, who is deaf/blind. He was to graduate from the Helen Davis State School for Severely Handicapped in Saint Joseph the following June (1994), and Vivian was troubled about his transition plans. There were no agencies or programs in the Saint Joseph area that could adequately address the needs of a young man who is deaf/blind.

Vivian had been discussing her concerns with Diane Landess, another mother who has a child with deaf/blindness at the Helen Davis State School. Both parents became acutely aware that there were no appropriate programs in the community for their children upon graduation. An adequate transition plan could not be developed for either youth.

Therefore, Vivian contacted the 307.11 Project and clearly laid out her apprehensions. As a result of her call to the 307.11 Project, a meeting was planned in Saint Joseph that included Vivian, Diane, representatives from the Albany Regional Center (including the director), representatives from Progressive Community Services, Buchanan County's Senate Bill 40 Board (including the director), and representatives from the state's 307.11 Project.

It became clear at that meeting that the transition issues facing Vivian and Diane were shared by the families of other youth with deaf/blindness in the northwestern corner of Missouri. As a result, on February 8, 1994, the Saint Joseph/Region 1 Deaf-Blind Task Force – the state's third local deaf/blind task force – was created.

Unlike the state and the other two previously formed local task forces (Saint Louis and Greater Kansas City), which were created largely by professionals, the Saint Joseph/Region 1 Deaf-Blind Task Force was created and continues to be driven largely through the efforts of two determined parents.

The task force was faced with addressing two tasks simultaneously. It had to work on creating a program and other supports for Vivian's son. At the same time, it had to address the issue of organizing itself into an effective task force. To assist the task force in designing a program centered around Vivian's son (rather than trying to make her son fit into a program), a Personal Futures Plan was conducted for Vivian's son. Meanwhile, the task force addressed the issues of securing funding for such a program as well as finding an agency that would provide the program. Through intensive collaboration between the Albany Regional Center, Progressive Community Services, and Community Recreation and Resocialization, funding was arranged, and a one-on-one program was created for Vivian's son. Since that time, a similar one-on-one program has been created for Diane's daughter, who graduated in June 1995.

The task force is currently addressing the issue of securing training for the direct service staff who work with these two youth. The training will need to address the areas of deaf/blindness, communication, deaf/blind calendars, orientation and mobility, etc. The task force is also working on continuing therapies for these two youth.

As the transition issues of these youth are being addressed, the Saint Joseph/Region 1 Deaf-Blind Task Force is expanding outward and will soon begin to identify many more deaf/blind consumers - of all ages - and the education, adult service, and other community agencies providing services to these consumers.

The Saint Joseph/Region 1 Deaf-Blind Task Force is not limited to addressing the service delivery needs of only those deaf/blind consumers living in Saint Joseph. The task force was created to address the needs of all deaf/blind consumers in the part of the state serviced by the Albany Regional Center (Region 1). This includes the counties of Atchison, Nodaway, Worth, Holt, Andrew, Gentry, Dekalb, Buchanan, Clinton, Harrison, Daviess, and Caldwell.

If you are interested in contacting the Saint Joseph/Region 1 Deaf-Blind Task Force for assistance and/or information, please contact the co-chairpersons for the task force:

— Diane Landess, parent, 3328 Burnside, Saint Joseph, MO 64505 (please contact via writing)

— Jan Rodgers, director, Family Institute of Kansas City. 301 State Line Rd, Suite 216, Kansas City, MO 63114; (816) 523-4440

FUNDING IN JEOPARDY

This funding alert was received from the National Coalition on Deaf-Blindness, dated July 20, 1995:

"As many of you are aware, the House Appropriations Subcommittee cut the discretionary programs by nearly 70 percent. Eight of the current 14 programs were zero- funded while the remaining 6, including deaf-blindness, were level funded.

If the House Committee responsible for the reauthorization of IDEA (Individuals with Disabilities Education Act) follows the Department of Education's proposed bill, they will include a section calling for minimum funding levels for low-incidence disabilities such as deaf-blindness. This was put in to ensure that the money currently used by the deaf-blind program ($12.8 million) would be maintained even if the current program was merged with others.

An additional concern cropped up this week that could jeopardize the $12.8 million by Deaf-Blind Services. Unfortunately, there is a provision in this section that says if the amount of money appropriate for *all* the programs in Parts C through G of IDEA (the discretionaries) falls below $254 million – the amount in FY 1995 – then the minimum funding levels would be reduced proportionately.

There are some in Washington who feel that since the amount appropriated for the discretionary programs is now $78.9 million, the services for deaf-blind children should receive slightly under $4 million.

While the House bill has not been made available at this date, it is *imperative* that the disability community contact the elected officials and advocate for full funding of the discretionary programs in IDEA."

For more information, contact:
— National Coalition on Deaf-Blindness, 175 North Beacon St, Watertown, MA 02172; (617) 972-7347 or Fax [617] 923=8076

SPECIAL NEEDS IN THE LUNCHROOM: MODIFYING SCHOOL MEALS FOR STUDENTS WITH SPECIAL EATING NEEDS

by Gloria Frolek Clark

Tacos, grapes, carrot sticks, an iced cinnamon roll, and milk. Sounds like a typical lunch, right? Most children have two options – eat hot lunch or bring lunch from home. But what are the options for children who choke on any foods except baby food, easily aspirate liquids (swallow liquids into the lungs), need low-calorie meals due to medical disorders, are allergic to certain foods, or are unable to chew food?

Consider Nicki, a 7-year-old girl with head injuries, who cannot chew food and needs it blended to the thickness of pudding. Nicki refuses to eat most vegetables and fruits. Her teacher and parents have noticed that if they mix her food with mashed potatoes, she will eat more. This is crucial because she has lost 5 pounds in the last year and is now below the fifth percentile when her height-to-weight proportion is graphed on a growth chart.

> *A "typical" lunch could be life-threatening to children with special needs*

Liquids also run down Nicki's throat too fast and cause her to choke. The school occupational therapist has recommended that the liquids be thickened using baby food cereal, yogurt, or blended fruit, such as applesauce.

How can Nicki's school lunch be modified to make it safer and provide her with the nutrition she needs?

School Requirements

The Rehabilitation Act of 1973 required recipients of federal funds to make their programs and activities accessible to all individuals with disabilities. Section 504 of the act incorporated new regulations for school meal programs into the Child Nutrition Program Regulations of 1988, commonly known as the breakfast and hot lunch program. These regulations require schools to modify or make substitutions in meals at no extra charge for students who meet the definition of having a disability and whose disability restricts their diet. A person meets this definition if he or she has a physical or mental impairment that "substantially limits one or more major life activities," has a history of having such an impairment, or is believed to have such an impairment.

Since the Child Nutrition Program Regulations are monitored through the U.S. Department of Agriculture (USDA) rather than the U.S. Department of Education, families and professionals who care for children with special needs are often not aware these regulations exist.

A variety of modifications and substitutions may be necessary to allow a student to consume the meals offered to students without special needs. Some students with gastrostomy tubes may require a liquid formula, while other students may require modifications such as:

- Substitutions of menu items to accommodate such dietary restrictions as allergies, or foods that don't puree well.
- Recipe modification to provide foods that are low or high in certain elements such as fat, sugar, fiber, or protein.
- Texture modifications such as thickening liquids, grinding, or chopping foods.
- Other modifications in food characteristics such as temperature, portion size, and nutrient composition.

It is imperative that nutritional value be considered when making any modifications to the meal. For example, if certain foods are prohibited, substituted foods should be similar in nutrient content.

Updated instructions issued in October 1994 by the USDA provide guidance to schools participating in breakfast and hot lunch programs. If a school is not a participant in this federal program, they may still be obligated to make modifications and substitutions based on the Individuals with Disabilities Education Act (IDEA). IDEA may require school food authorities to provide meals outside of the regular meal schedule or to provide services that are not usually required by the Child Nutrition Program.

Feeding and Nutrition Goals

Food modifications can be listed on a(n):

- Individualized Education Plan (IEP).
- Student Health Care Plan attached to the IEP.
- Goals-and-objectives plan related strictly to feeding and nutrition.

Even students who do not qualify for special education services are eligible for special food services as long as they meet the criteria for having a disability under the Rehabilitation Act of 1973.

In most cases, the school will require a physician's statement regarding the child's disability and related dietary restrictions. The school must determine if the student meets the regulatory criteria of the Rehabilitation Act of 1973, and is only obligated to provide those substitutions and modifications deemed necessary by the physician.

Changing the texture of the meal – by such processes as blending, pureeing, or chopping – does not require a physician's order, though it is helpful information for the school food service.

Inclusion

In addition to meal modifications, the regulations state that food services be provided in the most integrated setting appropriate to the special needs of the student. Unfortunately, students with special feeding needs often are not integrated into the lunchroom to the maximum extent possible.

A Team Effort

A team approach is critical for a child with feeding and nutrition problems. This approach has made a difference for Nicki.

Nicki has been followed closely by a nutritionist since her parents and occupational therapist became concerned about her weight loss. Her height and weight are being closely monitored by the school nurse and her regular physician. The nutritionist also discussed the need for supplemental vitamins and minerals because of the anticonvulsant medication she takes daily. The educational team has met to discuss the school food modifications that were needed for Nicki. The family, teachers, occupational therapist, and nutritionist provided input that was used to develop a plan. The physician has been kept informed of Nicki's needs and difficulties with the school lunch.

As a result of this team effort, specially prepared meals are now available each day for Nicki's lunch. Nicki's teacher keeps in constant contact with the school lunch supervisor regarding the modifications and how they are working for Nicki.

For more information about school food regulations, contact the food and nutrition service staff at your state Department of Education or your local school district administrator.

Printed by permission from: Clark, G.F. (1995). Special needs in the lunchroom: Modifying school meals for students with special eating needs. *Exceptional Parent (25)*, 45-46.

FREE MATERIALS

The Creating Employment Opportunities Project (CEO), located at the Center for Innovations in Special Education, has produced a video.

Disclosing Abilities is a video that addresses job search issues from the viewpoint of a person with a disability. Issues discussed are disclosure, accommodations, and the job search, as well as suggestions and tips from people with disabilities and employers who have been through the process. The video is available in open and closed captioning.

The CEO Project also has published three free handbooks: *Rights and Responsibilities of Faculty Concerning Students with Disabilities, Rights and Responsibilities of Employees*

with Disabilities on the Job, and ***Rights and Responsibilities of Students with Disabilities***.

The video and handbooks are available free from the Center for Innovations in Special Education while supplies last. They may also be borrowed through the Loan Package Program, 800-976-2473. Please specify LP #1301.

To purchase the video, contact: Instructional Materials Laboratory (IML), University of Missouri-Columbia, 2316 Industrial Drive, Columbia, MO 65202. IML may be reached at 800-669-2465. Please specify #92-6000-V when ordering. Cost of the video within Missouri is $20; outside Missouri, $25.

UPCOMING TRAINING OPPORTUNITIES

Missouri Innovations in Special Education Conference, "Working Together and How to Get There," co-sponsored by DESE (Division of Special Education), Missouri School for the Blind, Center for Innovations in Special Education, Missouri School for the Deaf, Project ACCESS, State Schools for Severely Handicapped, and the Missouri Technology Center for Special Education; November 13 (conference) and November 14 (post-conference workshops), 1995, Holiday Inn Executive Center, Columbia, MO. Contact: Kate Puyear, CISE, Parkade Center, Suite 152, 601 Business Loop 70 West, Columbia, MO 65211; (314) 882-0540 or 800-976-2473.

MO-TASH, "Working with People that Services Find Hard to Serve," September 28, 1995, St. Louis, MO. Contact: Vicki McMullen, 1155 Burch Lane, St. Louis, MO 63130; (314) 726-6696. Also presented in Kansas City on September 29, 1995. Contact: Mike McCarthy, 2220 Holmes, Kansas City, MO 64108; (816) 535-1745.

Missouri Parents Act (MPACT) announce the following upcoming training:

- Legal Rights, October 18, 1995, St. Louis, MO. Contact Fred Davis at (314) 997-7622.
- Legal Rights for Special Education, October 19, 1995, Liberty, MO. Contact: Joy McClaskey or Carolyn Stewart at (816) 531-7070.
- Communication Skills, Legal Rights, and the IEP Process, October 21, 1995, Aurora, MO. Contact: Sonia Moran at (417) 882-7434.

Linda K. Bradley, Editor
Roxanne V. Streeter, Design
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Missouri Deaf/Blind Project

Focus on Missouri Children and Youth with Deaf/Blindness **is published by the Center for Innovations in Special Education, University of Missouri-Columbia. Funding for this newsletter is through the Missouri Deaf/Blind Project and Missouri Department of Elementary and Secondary Education, Division of Special Education. If you have special needs as addressed by the Americans with Disabilities Act and need this publication in an alternate format, efforts will be made to meet your needs. For further information, contact Linda Bradley at the Center for Innovations in Special Education, Parkade Center, Suite 152, 601 Bus. Loop 70 West, Columbia, MO 65211, 800-976-2473 or Linda Van Eck Niedringhaus, Missouri School for the Blind, 3815 Magnolia Ave., St. Louis, MO 63110, 800-622-5672.**

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FOCUS

on Missouri Children and Youth with Deaf/Blindness

January 1994

USHER SYNDROME

This article is reprinted with permission from Sandra L.H. Davenport, M.D., Sensory Genetics/Neuro-development, 5801 Southwood Drive, Bloomington, NM 55437-1739.

WHAT IS USHER SYNDROME?

People with Usher Syndrome are born deaf or hard of hearing and, usually by teen-age, start losing vision due to Retinitis Pigmentosa, which is also called RP. People who are born deaf are also born without a sense of balance from the inner ear.

WHAT IS RP?

RP is a problem in the retina, which is the inside back layer of the eye. The RP causes the rods and then cones of the retina to gradually quit working. Rods control night vision and cones control day vision. These cells gradually deteriorate over many years causing vision loss. The usual pattern of loss is listed below but how fast the vision disappears is different from person to person. Also, some people may have periods of rapid vision loss followed by years when the vision stays just the same. There is not a good way of predicting how fast any individual person's vision will get worse.

SYMPTOMS	BEGIN AT	WHAT HAPPENS
Night vision loss (rod loss in retina)	0-20 years	Baby - does not reach for a bottle in the dark Young child - is afraid of the dark and will not go to bathroom without a night light Child - will not go anywhere at night without a guide or a light such as from car to house, to latrine at camp. -does not see the stars at night -misses information in class if lights are turned down -has problems in dark halls or dorm rooms in dim light Teenager - bumps into people or objects in dark hallways, theaters, teen centers, etc. or has trouble reading signs or speech. -may avoid going to social events at night. Adult - cannot see to drive at night -has problems in darkened restaurants or theaters -cannot see the stars -cannot do yard work or hunt at twilight
Peripheral vision loss (cone loss on sides of retina)	5-40 years	Early small blind spots are not noticed because moving the eyes around (scanning) fills in the missing information. When a ring-shaped blind spot is present, people become accident-prone but often do not realize why they did not see the oncoming person, bicycle or car, the object or child on the floor, the open door or object which has been moved to a new spot. Kids begin having problems playing team or ball sports because they lose track of the ball or do not see opponents coming from behind or from the sides. Friends call them "stuck-up" because they do not realize other kids are trying to get their attention. In class, the teacher has a harder time getting their attention and they miss information in group situations.

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SYMPTOMS	BEGIN AT	WHAT HAPPENS
Central vision loss (cone loss in the center of vision)	20-50 years	The field of vision in the center (where one looks directly at objects) gradually decreases from about 45 deg. to about 5 deg. over 1-3 decades. Then the vision tends to remain stable for a while and may even be 20/20 with or without glasses. When the field of vision is 20 deg. or less, this is declared legally blind even though the remaining vision may be very clear. At this state, stumbling and bumping into things becomes enough of a problem that mobility training for the individual improves confidence and ability to get around. Central vision can disappear completely, but most people can at least make out shapes or shadows until they are in their 60's or even later.
Cataracts (in the lens, not in the retina)	20-50 years	Estimates vary, but from 60-100% of people with Usher Syndrome will eventually get cataracts. Cataracts are densities or clouding of the lens in the front of the eye. Since light has to pass through the lens to get to the retina, a cataract either bends the light in the wrong direction or prevents the light from going through at all. Therefore, the person gradually notices colors getting duller and light getting dimmer. Objects become blurry and light glares. This is much like having dirty glasses or windshield. The more dirt, the harder it is to see. The same is true with cataracts. Cataracts can be removed by an eye surgeon. The results are usually excellent, but there are a few risks which each person should discuss fully with the eye doctor.

Just by looking at the eyes, doctors cannot tell the difference between the RP of people with various types of Usher Syndrome or people with RP alone. However, there may be some minor time of onset differences between the types because of when people first remember having symptoms of vision loss. To tell what type of Usher Syndrome it is, whether it is RP alone or another syndrome, requires a genetic evaluation including a thorough family history and examination. It is also important that the eye doctor orders an ERG (electroretinogram) to confirm the RP diagnosis.

WHAT ARE THE TYPES OF USHER SYNDROME?

At least two types of Usher Syndrome have been identified but many people do not fit these categories exactly. The major difference is in degree and pattern of the hearing loss and whether or not balance problems exist.

	USHER TYPE I	USHER TYPE II
Hearing loss	Children are born *profoundly deaf* or with just a little hearing in the low tones at loud levels of sound. Most but not all state that hearing aids help only a little or not at all. Some young children are showing benefit from cochlear implants.	Children are born *hard of hearing* with a sloping audiogram so hearing high pitches is harder than hearing low tones. Hearing aids are effective and most children are mainstreamed. Hearing loss does not change over many years but may go down with noise exposure or with aging. When vision gets bad, people think they are losing their hearing but, instead, they are losing their ability to lipread.

	USHER TYPE I	USHER TYPE II
Balance	Signals from the inner ear balance organ (vestibule) are *absent* at birth. This means that babies are late walkers and often seem to be clumsy. Once children learn to trust their vision and muscles, they walk, run and do physical activities normally. When they begin to lose their vision, either at night or with peripheral vision loss, they again feel unsteady and have to get used to the decreased vision.	Children are born with *normal* inner ear balance organ and do not have problems with balance.
RP	Night vision problems may be present as babies or preschoolers. Peripheral vision may be moderately affected by early teenage.	May be the same as for Type I, but some have no eye problems at all until mid to late teenage.
Other problems	None	None

Some authors have stated that mental retardation and/or mental illness affects up to 25% of people with Usher Syndrome. Many of us do not believe this, but more thorough research needs to be done in this area. People who have both hearing and vision impairments may be mislabeled as mentally retarded because they did not have the right tests or the right educational setting. Most, if not all, people with Usher Syndrome get depressed when they lose a lot of vision. Psychiatrists who are not familiar with how deaf-blind people react to depression may think these people are psychotic when they are just severely depressed.

OTHER CAUSES OF HEARING LOSS AND RP

About a dozen other conditions exist that can be confused with Usher Syndrome because they have both hearing impairment and retinal disease. The retinal disease may be actual RP, atypical RP or conditions that look like RP on the retina but are not. One example is that sometimes Usher Syndrome is diagnosed as Rubella Syndrome (from German measles during pregnancy). All of these other conditions have additional problems such as neurologic problems, obesity, extra fingers and toes, problems with short stature, etc.

Because there are so many conditions, it is important that each person with Usher Syndrome be seen by a geneticist to be sure the diagnosis is correct.

WHAT CAUSES USHER SYNDROME?

Usher Syndrome is inherited from the parents even though the parents are unaffected. In fact, the person may be the only one affected in the entire family on both sides for generations. It is still genetic and is inherited in an "autosomal recessive" manner. This means that the individual with Usher Syndrome has a double dose of a recessive (weak) gene. Since all genes come in pairs, one of the Usher genes came from the mother and the other from the father. Both parents are carriers which means each has one Usher gene but also has a normal (dominant or strong) gene at that location. Therefore, neither parent has hearing impairment or RP.

In the last two years we have now found three separate genes which cause Usher Type 1 (two are located on chromosome #11 and one on chromosome #14) and one which causes Type II (on chromosome #1.)

CAN A PERSON BE TESTED FOR THE USHER SYNDROME GENES?

Yes, if there is more than one person affected in the family and if enough other relatives can be tested to be sure the right location is identified.

No, if there is only one person affected or none, such as an unaffected spouse or a person who has a hearing impairment but no RP.

The genetic research is still in the early stages. If there are 2 or more people in the family with Usher, the testing can be done and is pretty accurate. However, this is done by "linkage analysis" which means that several people need to be tested to find the right location of the gene. The locations are not yet precise. In other words, the researchers have found the right neighborhood but not the right house address. In the future, once the right address is found, anyone can be tested.

If you want to be part of the research to find the exact location of the genes for Usher Syndrome and to find out what these genes do in the eyes and ears to cause RP and hearing loss, please write to:
The RP Foundation Fighting Blindness, 1401 Mount Royal Avenue Baltimore, MD 21217 (301) 225-9400 (Voice) (301) 225-9409 (TDD) 1-800-638-2300.

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RESOURCES

Horticulture Program

Perkins School for the Blind proudly announces its newest publication, *Horticulture Program*, an exciting addition to the field of horticulture therapy. The first handbook of its kind, its topics include planting, crafts, ideas for adapting gardening equipment, as well as vocational and sensory training. The handbook itself is visually very pleasing with colorful photographs and layout, technical illustrations, and black and white demonstration photos.

The purpose of this booklet is to share with parents and professionals some of what we have learned over the past 14 years since horticultural therapy has been part of the curriculum at Perkins. It provides a brief overview of the beginning of the program. More important, it shows the program in action, portraying some of the individuals who have benefitted and highlighting some of the adaptive equipment and creative teaching methods that make the program work so well. The hope is that this booklet can be a springboard for horticulture programs in other schools and agencies or in settings as diverse as nursing homes, rehabilitation hospitals, horticulture associations, cooperative extension services, garden clubs involved in garden therapy, vision associations, libraries, and special education and vocational programs in the United States and in countries around the world.

Copies are available for $10.00 each. For further information please contact Deirdre Carty, at Perkins School for the Blind, 175 North Beacon Street, Watertown, MA 02172, or call (617) 972-7339.

MISSOURI LINC MODULES

Two new information modules are available from Missouri LINC. They are:

Strategies to Assist Teachers with Parent Involvement. Parent involvement is a key element in the transition process. This module provides assistance to teachers on ways to include parents in their child's future planning.

Involving Students in Planning for Their Adult Life. This module gives suggestions to teach students to be more actively in their transition planning process.

To receive a copy of these modules, contact Missouri LINC, 401 East Stewart Road, Columbia, MO 65211 (314) 882-2733, (800) 392-0533 (Missouri only).

Linda K. Bradley, Editor
Linda Van Eck Niedringhaus,
Missouri Deaf/Blind Project

Focus on Missouri Children and Youth with Deaf/Blindness **is published by Missouri LINC, University of Missouri-Columbia. Funding for this newsletter is through the Missouri Deaf/Blind Project and Missouri Department of Elementary and Secondary Education, Division of Special Education. If you have special needs as addressed by the Americans with Disabilities Act and need this publication in an alternate format, reasonable efforts will be made to meet your needs. For further information, contact Linda Bradley at Missouri LINC, 401 E. Stewart Rd., Columbia, MO. 65211, (800) 392-0533 or Linda Van Eck Niedringhaus, Missouri School for the Blind, 3815 Magnolia Ave., St. Louis, MO. 63110**

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Columbia, MO 65211

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Attention: Parents of Children with Deaf/Blindness

FOCUS

on Missouri Children and Youth with Deaf/Blindness

April 1994

MORE ABOUT USHER SYNDROME

The first two articles of this issue of the FOCUS newsletter are reprinted by permission from Sandra L. H. Davenport, M.D., Sensory Genetics/Neurodevelopment, 5801 Southwood Drive, Bloomington, NM 55437-1739, (612) 831-5522. These articles are the second of a two part series on Usher Syndrome.

WHAT CAN BE DONE ABOUT USHER SYNDROME?

There is no cure for either the hearing loss of Usher Syndrome or for the Retinitis Pigmentosa (RP). There is also no way to prevent it. Prenatal diagnosis is not available yet but will be when the gene testing is more accurate.

Nevertheless, a lot can be done for Usher Syndrome. The hearing loss sometimes can be treated with hearing aids or cochlear implants depending on the Usher type. Most important, however, is that children be placed in good educational programs, that adults can take advantage of the appropriate rehabilitation programs and that both children and adults can meet other people with Usher Syndrome and their families.

The earlier the diagnosis of RP is made, the easier it is for both the child and the parents. By the time teenage years roll around, hearing impaired kids think of themselves as deaf or hard of hearing only and plan their futures accordingly. If they know they have a vision impairment that will get worse over time, they can learn what that means and how to cope with it in stages. They and their families can meet other people with Usher Syndrome, of which there are at least 10,000 in the United States alone. From others they can learn what the problems and the joys are, how to adapt in order to lead a full and satisfying life.

Every attempt should be made to locate professionals and agencies that have expertise in Usher Syndrome. Often the best place to start is by calling the Helen Keller National Center to find out how to contact their regional representative. That representative usually knows the most helpful resources in each state or at least the place to start.

Helen Keller National Center for Deaf-Blind Youth and Adults, HKNC National Headquarters, 111 Middle Neck Sands Point, NY 11050 (516) 994-8900 (Voice and TDD).

FOR SINGLE MOM, USHER DIAGNOSIS IS HEARTBREAKER

by Joanne Wiltscheck

It was December, 1984 and I was living in the state of Washington. My carefree years suddenly came to an end with an unexpected pregnancy. I was not married. What was I going to do?

My partner in this dilemma voted for an abortion. I didn't know what I wanted. I wished I could see the future . . .

If I had known . . . the amount of emotional pain involved with a disinterested partner . . .

If I had known . . . the pregnancy would cause me to have numerous surgeries which would put me on medical leave for 10 months . . .

If I had known . . . that my child would be born deaf and gradually lose his vision . . .

If I had known . . . I would have probably made another choice . . .

Thank God for not giving us the ability to see into the future!!

Why? Because I wouldn't trade my son for anything or anyone in the whole wide world! I can't imagine life without him! Nothing could replace my love for him!

Corey is his name. He was a beautiful baby with long dark hair. It was not until I returned to work, 10 months after his birth, that I suspected a hearing problem.

Suspicion led to tests and tests revealed a profound hearing loss. What a shock! I cried. I cried all night long. But his deafness did not throw me into despair. By the next day I could accept it.

Corey was 19 months old when I learned I needed another surgery. This time I wanted to go home, home to Minnesota. Home to where my family was.

While recovering, I grew increasingly concerned over Corey's gross motor skills. He was barely starting to walk and was awkward and off balance. His motor skills were always a couple months behind. As a baby, his neck needed support for the longest time.

I sought answers from specialists. On September 29, 1987, at approximately 2:00 p.m. came the diagnosis. Usher Syndrome. It was devastating. This time God went overboard. He wasn't being fair. This time it took weeks to go through the grieving process. My heart and soul were bleeding. Endless questions and no answers. If only I had known where to turn.

By age two, a teacher for the hearing impaired was visiting my home two days a week in the morning to work with Corey. She helped me ease the pain.

She joined in my search for answers and put me in touch with the right people.

It wasn't long before Dr. Sandra Davenport had us participating in a research project in Boy's Town, Nebraska. Between Boy's Town and spending a week at Galludet University for a Family Learning Vacation on Usher Syndrome, I was able to find most of the answers I needed. The more I knew, the better I felt.

Corey is now a seven-year-old, well adjusted, and a happy boy. He is curious and bright. We moved to Faribault, Minnesota three years ago so he could attend the Academy for the Deaf. The school has been terrific!

Last summer I made the difficult decision of getting Corey a cochlear implant. Now I am grateful. Corey is obviously benefitting from it and I believe it will ease the impact of vision loss. I have no question of Corey's ability. It's there. I do question the system. Will it meet his needs? Or will he fall through the cracks?

Corey has given me a whole new perspective on life. He is teaching me the value of sight, the significance of sound, and the power of touch.

For more information about Usher Syndrome or to subscribe to *Usher Family Support*, contact Helen Anderson, 4918 42nd Avenue South, Minneapolis, MN 55417.

"FRIENDS" FOR FAMILIES WITH EXTRA-SPECIAL NEEDS . . .

by Viki Vogli-Phelps

Chris and her two-year-old son, Joey, look forward to their weekly afternoon visits from Jean. Jean, age 60, is a Family Friends volunteer.

Last week Jean brought a battery-operated, dancing clown toy. The clown is adapted with a saucer-sized switch that Joey can press with his forearm to make the clown dance. Joey loves the toy and Jean's excited face while they play together.

Joey has Cerebral Palsy and his mother bears the extra responsibility that a child with a disability demands. Needing help and some respite from daily tasks, Chris asked to be placed on a waiting list to receive the services of a Family Friends volunteer. She was elated when just a few months later Jean arrived at their home as their new "Friend". When Jean comes to visit, Chris can have a few moments to herself, or if she feels like talking, Jean is there to listen. In addition to the benefits to this family, this volunteer job is important to Jean; she senses that she is an accepted part of the family.

Chris, Joey and Jean are a composite of various scenarios, but they represent people and situations that are very real.

The Family Friends program matches a person, age 55 or older, with a family that has a child with a disability or chronic illness. The Family Friends (FF) program, developed by the National Council on Aging, began in 1986. There are now twenty-five Family Friends programs throughout the country.

Susie Newman is the Coordinator of the Family Friends program in Kansas City. The Program is sponsored by and housed at Children's Mercy Hospital; primary funding is granted by the Administration on Aging, Department of Health and Human Services. The UMKC Institute for Human Development is conducting the national Family Friends program evaluation. So far, Susie has matched eight families with "friends" and six more "friends" are placed in day care centers to help with specific children. There are ten families on the FF waiting list. Susie is always in the process of recruiting and training new volunteers. Advertising for volunteers metro-wide helps to ensure "a close, geographical proximity between the family and volunteer, which is a priority."

These matches don't come easily. There are extensive interviews with the volunteers, legal investigations, and a required health screening that includes a TB test. Once the volunteer is accepted, the FF program provides 15-20 hours of initial training, monthly volunteer support groups, inservice training opportunities and reimbursement for travel expenses. Both the family and the friend try to commit to one visit per week for at least nine months. But the biggest part of the commitment is just being a friend!

For more information about the Family Friends Program, contact: Susie Newman, Program Director; Family Friends Program, The Children's Mercy Hospital, 2401 Gillham Rd, K.C., Missouri 64108, (816) 234-3676.

LEARNING OPPORTUNITIES

MISSOURI SCHOOL FOR THE BLIND

Missouri School for the Blind is offering several upcoming training opportunities:

April 14-17
- AER Administrators Conference
- AFB Midwest Regional Braille Training Program

June 16-18
- Southeast Regional Early Childhood Sensory Impaired Conference for Parent Advisors

July 30-31
- Family Learning Vacation
- Weekend with the Experts; Cortical Blindness

For more information, please contact Jacqui Grable at (314) 776-4320 or (800) 622-5MSB.

FIRST COME, FIRST SERVED

One half voucher is available to cover half the cost of a graduate course at Boston College (1 1/2 credit hours) in vision or deaf/blind studies. The voucher expires October 1994. Housing may be available at the Perkins School for the Blind.

If you are interested please contact Linda Van Eck-Niedringhaus at (314) 776-4320.

SUMMER COURSE ON DEAF/BLINDNESS

The Colorado Department of Education and the University of Northern Colorado are co-sponsoring a second Kephart Symposium graduate course on deaf/blindness. The course, "Assessment into Intervention: Effective Strategies for Students with Deaf/Blindness", will be held in Vail, Colorado on July 25-29, 1994. The course instructor will be Dr. Kay Alicyn Ferrell. Presentations topics will include:

- *Psychological Views of Deaf/Blindness* by Dr.Harvey Mar
- *The Infant, Toddler, and Preschool Child* by the Colorado Hilton Perkins Early Intervention Assessment Team
- *The School Aged Child* by Dr. Barbara McLetchie
- *Social Interaction/Inclusion/Intervention* by Madeline Milian-Perrone and Nancy Sail
- *What Professionals Need to Know* by a panel of parents and consumers

For more information about course content, Please contact Tanni Anthony, CDE, 201 E.Colfax Avenue, Denver, Colorado 80203 (303-866-6681). For information on course registration, please contact Marsha Woodruff, UNC, Division of Special Education, Greeley, CO 80639, (303) 351-2893.

MISSOURI LINC SUMMER EDUCATIONAL OPPORTUNITIES

L/F372 Methods in Vocational Education for Students with Disabilities and Disadvantages
June 13-17, 1994, 1-5 p.m., Columbia, MO

Course Description
General, special, and vocational educators who teach students with disabilities or disadvantages will be presented current information on: student assessment, learning styles, transition, functional curriculum, integration of academics in vocational education, legislation, strategies, community networking, and job development. Missouri LINC staff along with guest lecturers will provide current information and instructional activities.

L410 Leadership in Transition
July 11-14, 1994, 1-5 p.m., Columbia, MO

Course Description
This institute will focus on developing leadership skills that will assist educators in improving the transition of students with disabilities from school to adult life. Students will be required to conduct a needs assessment, develop and implement a program improvement plan and demonstrate change in their district's implementation of transition services for students with disabilities.

Course Requirement
This institute spans the 1994 summer session and the 1994-95 academic year. It is offered for one to three semester hours of credit. Students are encouraged to sign up for all three hours to gain the most from this training. For three hours of credit students will be required to attend class from July 11-14, complete assignments, and commit to two full-day follow-up classes throughout the 1994-95 school year. The credit will be awarded after completion of the course requirements.

Students in this institute are required to register as teams with a minimum of two members. Team members may include educators, administrators, parents, or community members who are concerned about the future of students with disabilities in their district. The registration must be accompanied by a letter of support from your school administration.

For more information about these courses, please contact Missouri LINC, (800) 392-0533.

Linda K. Bradley, Editor
Linda Van Eck-Niedringhaus,
Missouri Deaf/Blind Project

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Attention: Parents of Children with Deaf/Blindness

FOCUS on Missouri Children and Youth with Deaf/Blindness

Summer, 1994

Personal Futures Planning

by Larry Rhodes

WHAT IS IT?

Personal Futures Planning (also sometimes called *Individual Futures Planning*) or *PFP*, for short, is an ongoing process that focuses on the strengths and capabilities of an individual with disabilities (called the *focus person*). This process then leads to the creation of a vision of a desirable future for that individual. It provides a framework for translating that dream for the future into a plan, and then that plan into reality. It does this by providing an ongoing means to creatively problem solve difficulties encountered along the way.

This is accomplished by the efforts of a small group of people dedicated to the focus person, called a *Circle of Support*. This circle of support meets on a regular basis over time to ensure that changes occur that are needed to bring about that vision of the focus person's future.

WHO ARE THE IMPORTANT MEMBERS OF THE CIRCLE OF SUPPORT?

The focus person.

A champion or advocate who will go to great lengths to make things happen for the focus person. This is generally a parent or other member of the focus person's family. Often it is a close and caring friend of the focus person.

The facilitator who leads the circle of support throughout the PFP process. Sometimes the facilitator may also be the champion.

Other family members who contribute information about the focus person's history and who may take an active part in creating and implementing the dream.

The friends of the focus person and/or her/his family who wish to contribute information and who desire to make the focus person's life better.

The focus person's teacher(s) if the focus person is still in school (or has recently graduated). Often the focus person's therapist(s) also become part of the circle of support.

Adult service providers who can make important connections for the circle of support. These service providers may also be able to secure funding for activities connected with the focus person's plan.

Other professionals (advocates, specialists, and so on) who can be called on from time to time for advice and assistance.

STAGES OF PFP PROCESS

Stage 1: Setting Up the Personal Futures Planning Process.

It is important that there be an initial meeting of the facilitator, the focus person, and champion (remember, the champion and the facilitator can be the same person) and the focus person's family. During this meeting the facilitator will answer any questions that the others may have about the Personal Futures Planning (PFP) process. Then the group will discuss how they want to run their PFP sessions.

An important thing that will be determined at that meeting is: Who should be invited to participate in the circle of support at the next meeting? Those people to be considered for the next meeting are: those who care about the focus person and know that person well, those who are the most committed to work for change in the focus person's life, and/or those who are connected to the community and local agencies that can offer assistance. Another *very* important thing to be determined at that meeting is: How can the focus person be included? What can be done to increase the focus person's participation in the circle of support?

Stage 2: Developing the Personal Profile.

At the next meeting (and perhaps the next few meetings), the circle of support explores the life story of the focus person. This exploration is called *developing the personal profile*. During this stage, which usually has more than one meeting, the members of the focus person's circle of support analyze what the focus person has accomplished in her/his life. The members of the circle of support identify the focus person's *capacities* (or capabilities/strengths). Information gathered during the PFP is documented through a series of pictorial records called *maps*. Maps are a graphic way to organize and illustrate information obtained about the different aspects of the focus person's life. These maps are created as the members of the circle of support tell their stories about the focus person. Maps that are created during this process include:

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Background. This map builds understanding with the members of the Circle of Support of the life experiences of the focus person and her/his family. It graphically demonstrates the significant life events such as traumas and losses. More importantly, however, it features those positive experiences which can be used as building blocks for future dreams.

Relationships. The purpose of this map is to identify the personal support and assistance available for the focus person. Not only does this map identify those supports already being used, but it also helps identify other potential supports.

Places. This map examines where the focus person spends her/his time by looking at the pattern of her/his daily life. This map helps illustrate that individual's participation in integrated and segregated settings. It also helps identify possibilities for increased participation in the community.

Choices. This map depicts the degree of control the focus person has over her/his own life by examining the choices that person makes about such things as personal care needs, how to use recreation time, what foods to eat, who to spend time with, etc.

Hopes and Fears. This map enables the focus person and her/his circle of support to explore the hopes and ears about their dreams of the future.

This stage of the PFP process often amazes the participants. Accomplishments and strengths that were not previously recognized become very apparent. Often members of the circle of support learn many new things about the focus person.

As these maps are completed, they are generally hung around the room for everyone to see. Slowly a whole picture of the focus person emerges. A sample of one such map on page 3.

Stage 3: Creating the Dream.

This stage is the critical stage of the PFP process. This is when things really begin to happen. By this point, the inventory of the focus person's capacities has been completed (the personal profile). As stated, the process of identifying the focus person's capacities is generally very "eye opening" to everyone involved - even to those individuals who know the focus person best! With that new insight about the focus person percolating within everyone's minds for a few weeks, the members of the focus person's circle of support are now ready to create a comprehensive picture - or vision - of the focus person's future. The process does not stop there, however, because the circle of support also identifies the steps needed to make this future become reality.

When developing the vision of the future, several aspects for the focus person's life should be addressed. Questions can be used to help the circle of support look at all aspects of the focus person's life. Questions that help develop the dream are: How does the focus person envision her/his living situation? How would she/he like it to be? What would the focus person's work be? How does the focus person see herself/himself involved in the community? Consider asking questions that also relate to the areas of relationships, health, continuing education, communication, recreation, and so on. Everything that is important to the focus person should be covered. The map that records this vision of the futures becomes the ***futures map***.

To help the circle of support turn the dreams from the futures map into a reality an action plan must be developed. First the members select and start working on one or two priority areas. They brainstorm and develop strategies that will take the focus person closer to those one or two goals. Often obstacles are identified at this time. Members of the circle of support are encouraged to creatively solve problems by developing and using a map that addresses opportunities and obstacles. This will help members collectively brainstorm solutions to any barriers that stand in the way. Members are encouraged to think of the support found in each community and not be tied to existing services for people with disabilities. Individuals then take on responsibility for working on specific tasks identified as needed to fulfill the goal(s). This ***action plan*** should clearly state who will do what. A copy is then given to everyone attending to help them remember their responsibilities.

This stage is also a turning point for the circle of support itself. Up until this point, the circle of support met to develop a personal profile and to create a dream. Now the circle of support works to make that dream come true. By this stage, people are identified in the circle of support who want to be part of the ongoing action group, the ongoing circle of support. Some people may leave the group and others may join over time.

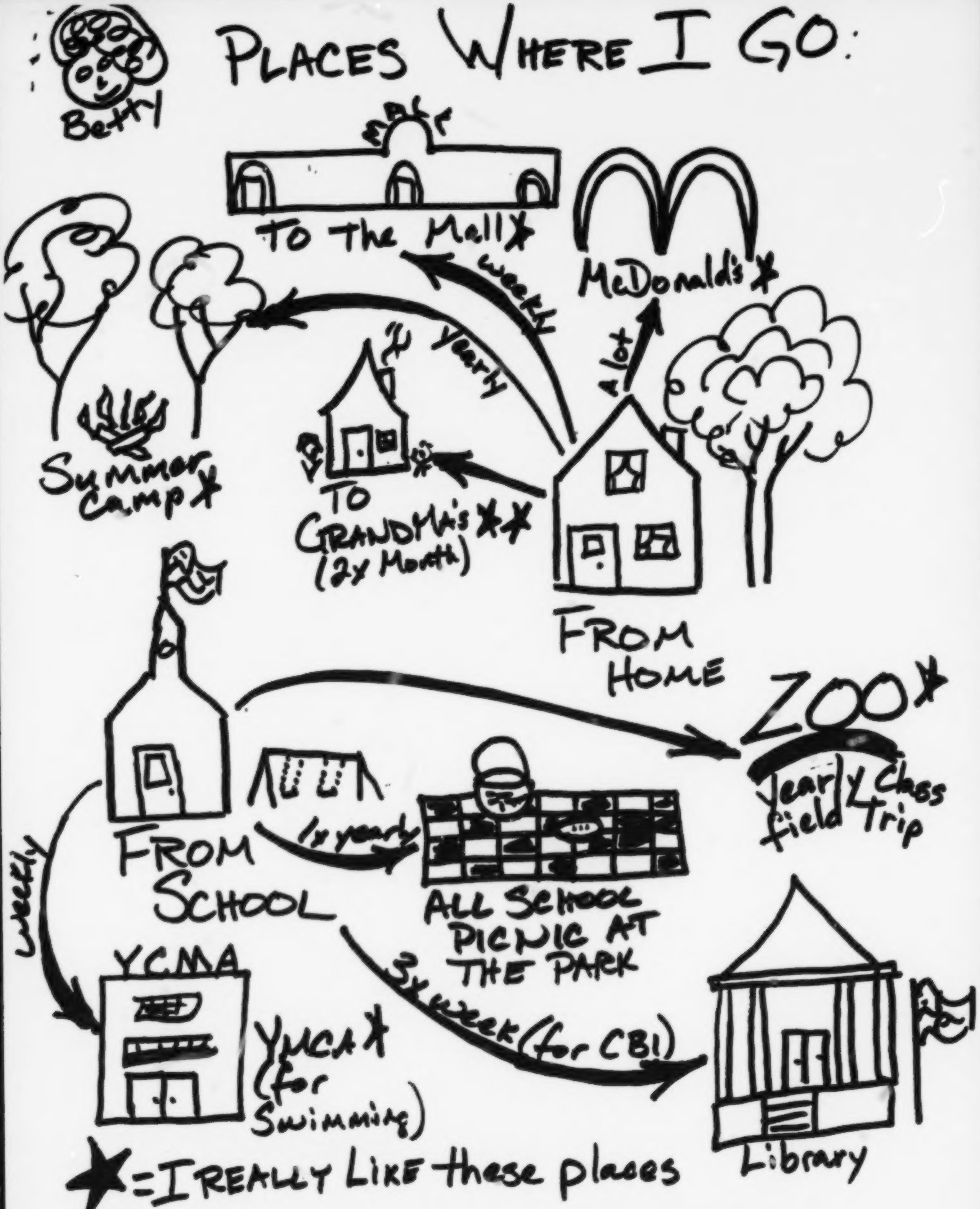
Stage 4: Making the Dream Real.

The circle of support meets regularly (about every month or two) during this stage to report back on progress made in reaching the goal(s) in the action plan. Sometimes small subgroups meet to work on specific tasks between each meeting of the circle of support. At each meeting, the members share the successes that have been achieved. If any obstacles have been encountered, the circle of support can develop new strategies to overcome those obstacles. A new action plan is developed, tasks assigned, and the next meeting date is set. As each one of the futures planning goals is achieved, the circle of support looks back at the rest of the goals listed in the focus person's futures plan and determines which goal next needs to be addressed.

WHEN SHOULD THE FOCUS PERSON HAVE PERSONAL FUTURES PLANNING?

The focus person should have a PFP whenever needed. Personal Futures Planning is an effective tool to help bring about needed change in the life of an individual who has a disability. It is also very effective in helping such an individual make any kind of transition. If the focus person is a student starting the transition process from school to adult living, it is suggested to start a Personal Futures Plan for the student at least *two years* before graduation from school. (NOTE: Personal Futures Planning is generally not started until a student is about 14 years old when the student, the student's family, and the school need to start transition planning to prepare the student for adult living.)

PLACES WHERE I GO:


Betty
To The Mall ★
weekly
McDonald's ★
A lot
Yearly
Summer Camp ★
TO GRANDMA's ★★ (2x Month)
FROM HOME
ZOO ★
Yearly Class field Trip
FROM SCHOOL
1x yearly
ALL SCHOOL PICNIC AT THE PARK
weekly
YCMA
YMCA ★ (for Swimming)
3x week (for CBI)
Library
★ = I REALLY LIKE these places

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WHAT ARE THE BENEFITS OF PFP?

The Personal Futures Planning process assists the focus person in developing a better self-image. By providing an opportunity for the focus person to participate more fully in planning and decision-making and by increasing that person's social network and natural supports, the focus person is also given an opportunity to experience personal growth.

Not only does the focus person obtain benefits from the PFP process, but so does the focus person's circle of support. Those individuals, particularly if they are not family members, become more responsive to the needs of each individual with disabilities. Family members also take on a more active role in the planning process of the focus person. By strategic planning and creative problem solving, new options in education, housing, recreation, and so on become available or are created.

HOW DOES AN INTERESTED PERSON FIND A FACILITATOR FOR A PFP PLAN?

Depending where that person lives in the state, it may be relatively easy or very hard to find a trained PFP facilitator. Consider contacting the special education department of the local school district and/or the nearest Department of Mental Health Regional Center Office to see if they have a listing of PFP facilitators. Check with parent groups, such as MPACT, for a referral to a facilitator. Also contact the Missouri Deaf-Blind Project's office at the Missouri School for the Blind (314) 776-4320 ext. 250 for a list of facilitators.

RESOURCES

If you are interested in more information about Personal Futures Planning, the following books and newsletters are recommended:
It's Never Too Early, It's Never Too Late and Making Futures Happen: A Manual for Facilitators of Personal Futures Planning by Beth Mount and Kay Zwernik. Both of these books were published by the Metropolitan Council of St. Paul, MN. You can receive one free copy of each book by calling (612) 296-4018.

Transition and Individual Futures Planning: For People with Deaf-Blindness and Developmental Disabilities and Their Families prepared by the ARC - King County and Common Ground. Contact these agencies directly for information about securing a copy. There address and phone numbers are:

The ARC - King County
10550 Lake City Way, NE
Seattle, WA 98125-7752
(206) 364-6337

Common Ground
107 Cherry Street #410
Seattle, WA 98104
(206) 461-4500

Also contact the Helen Keller National Center - Technical Assistance Center and ask for Volume 6, Number 2, Winter-Spring 1992-1993 issue of their newsletter..

Helen Keller National Center
Technical Assistance Center
111 Middle Neck Road
Sands Point, New York 11050-1299
(516) 944-8900 (Voice/TDD)

Larry Rhodes is the Transition Coordinator for the Missouri Deaf/Blind Project, Missouri School for the Blind, 3815 Magnolia Avenue, St. Louis, Missouri, 63110, (314) 776-4320, ext. 255

Linda K. Bradley, Editor
Linda Van Eck Niedringhause, Missouri Deaf/Blind Project

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Address Correction Requested

Attention: Parents of Children with Deaf/Blindness

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VII.

Component III

Family Services Coordinator

Final Report

October 1, 1994 - September 30, 1995

Family Institute of Kansas City
9225 Ward Parkway - Suite 105
Kansas City, Missouri 64114

FAMILY INSTITUTE OF KANSAS CITY, INC.
A NOT-FOR-PROFIT ORGANIZATION

Annual Report
FY 1994-95

To: Linda VanEck
Missouri School for the Blind

From: Jan Rodgers
Family Institute of Kansas City, Inc.

The following report highlights the strengths and accomplishments related to the objectives sub-contracted by this agency.

OBJECTIVE 2: TO ADMINISTER A RESPITE CARE PROGRAM AND ACT AS A RESOURCE TO OTHER RESPITE CARE PROGRAMS SERVING PERSONS WITH DEAF-BLINDNESS.

ACCOMPLISHMENTS:

Family Institute of Kansas City administered a respite care program in St. Louis City and County, that served 200 county, and 115 city consumers including Deaf-Blind and other multiply impaired consumers. During this project period over 100 county, and 60 city consumers enrolled in the program enabling them to receive respite services.

St Louis Respite Care utilizes an individualized approach to assure service needs are met for the Deaf-Blind consumer and their family.

Providers are independent contractors and are chosen by the families. This model developed by Family Institute of Kansas City,Inc in 1980 has been replicated by many other Respite programs in Missouri.

Family Satisfaction is reported monthly on the required service report. On a 5 point scale the overall satisfaction is 4.85. The high degree of satisfaction is related to family participation in provider recruitment, and family scheduling and utilization of the service.

Multi-agency funding was secured to expand this program. Funds from Mo. Dept. of Mental Health, Federal Respite monies, Senate Bill 40 funds from St. Louis City, MRDD REsources; and county, Productive Living Board were utilized. These resources totalled $800,000. for the program.

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A Respite Care Procedural Manual was developed to facilitate service delivery, and enable replicability in other areas.

Program staff participated in both the local Respite Coalition, and the Statewide Missouri Respite Coalition to enhance the overall service delivery system and offer support and assistance to other respite programs.

Lastly, a multi-component proposal was submitted to the Productive Living Board in St. Louis County to provide the majority of Respite Care and other family support services to consumers in this geographic region. It was a bidding process,and though we did not receive the bid a variety of innovative service components were developed for future implementation. The majority of the services were family driven to enhance and utilize natural supports to extend family support and respite. The detailed plan of operation will be utilized in program development for Family Support services for Deaf-Blind consumers and their families.

The accomplishments in this objective exceeded projected outcomes.

OBJECTIVE 7:TO COOPERATE AND COORDINATE THE DELIVERY OF SERVICES WITH OTHER RELATED STATE AND LOCAL AGENCIES.

ACCOMPLISHMENTS:

Participation in a leadership role as the Chairperson of the Statewide Deaf-Blind Taskforce, Chairperson of the St. Louis Deaf-Blind Taskforce, Chairperson of the St. Joseph Deaf-Blind Taskforce, and to a lesser degree participation in the Kansas City Deaf-Blind Taskforce. A mid Missouri Task force is also in the process of development and will become active during the next fiscal year.

Active leadership to develop these local Taskforces, resulting in the implementation of a collaborative multi-agency network to effectively address the challenging issues effecting individual consumers.

In both the St. Joseph, and St. Louis Taskforces emergency consumer needs prompted the Taskforce development.Individualized services were developed cooperatively developed to address these emergencies.

Local Taskforce meetings are held monthly, and statewide meetings occured bi-monthly. Participating agencies included the youth and adult service providers to assist in successful transition services for Deaf-Blind consumers.

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The primary purpose of the State and local Taskforce model is to identify, and address difficulties related to service delivery systems on a case by case basis. Whenever possible, service delivery solutions were designed and implemented.

Extensive training and technical support has been provided to agencies participating in the Taskforces to enhance service delivery capabilities and knowledge of the unique needs of Deaf-Blind consumers.

Leadership was provided to receive Technical assistance from HKNC Tac during this period. Three workshops were designed to meet the needs of the Taskforce participants. They were well attended by all Taskforces. Funding for these workshops was provided by participating agencies increasing cooperation, collaboration, and a feeling of ownership in Taskforce development.

Additional HKNC Tac consultation was arranged for specific consumers and program staff.

Taskforce development and participation has enhanced the Individual action plans, and and the ability of IHP teams to meet consumer needs.

Taskforce development has also enhanced and extended the use of natural supports in the community for these Deaf-Blind consumers.

The following accomplishments are a direct result of the State and Local Taskforce development:

The development of a St. Louis Training team that includes participating Taskforce members. The training team provides monthly orientation for new staff, and plans and conducts inservices to address the needs of Deaf-Blind consumers.

A supported living project was funded by senate bill 40 funds for this fiscal year to provide additional training funds and support to facilitate transition services for Deaf-Blind consumers. These funds assisted in the HKNC training.

Personal Futures training has been provided to many Taskforce participants. Personal futures planning has been incorporated into the planning process for many Deaf-Blind consumers.

Exploration by the Taskforces to implement a Deaf-Blind Medicaid Waiver.

Workshop presentations for local, state, and national conferences sharing the Missouri Taskforce Model.

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Interactional accomplishments that have occured as a direct result of the Taskforce Model:

These accomplishments are the most difficult to assess, and are essential to enhanced service delivery.

The Taskforce Model has provided a relationship structure for many agencies and individuals to work cooperatively and collaboratively for a common goal. This has provided an opportunity to work in partnership, and develop alliances and positive relationships between agencies that historically had not occured.

The communication network that has been established between agencies and service providers has enhanced responsiveness to consumer emergencies,and has facilitated positive problem solving strategies.

Current goals include the further development of the Taskforce Model to create a statewide service matrix, and the compilation of current resources and a directory of Taskforce participants so communication between counterparts can occur more easily across the state.
Internet, and E mail possibilites are also being explored.

The accomplishments exceeded our goals and objectives in this area.

VIII. Component IV

Transition Planning Consultation Services

Final Report

Grant Year: 1 October 1994 - 30 September 1995

Larry Rhodes
Transition Planning Consultant (TPC)
Missouri 307.11 Project
Missouri School for the Blind
3815 Magnolia Avenue
Saint Louis, Missouri 63110

INTRODUCTION

The following report is an update and summative accounting of the activities of the Transition Planning Consultant (TPC) of the Missouri 307.11 Project from the period 1 October 1994 through 30 September 1995. It is intented to give quantitative and qualitative information about the seven objectives of the 307.11 Grant in which the Transition Planning Consultant shares responsibilities with other Missouri 307.11 Project Staff.

Objective 1: To provide a state outreach and home intervention program to children who are deaf-blind, birth to five years of age, and their families.

Objective 2: To provide technical assistance to public, private, and State agencies on basic skills, sensory training, technology, best practices, transitioning, family dynamics, and respite care orientation.

Objective 3: To provide information assistance to families, SEAs and LEAs on basic skills, sensory training, technology, best practices, transitioning, family dynamics and respite care orientation.

Objective 4: To improve consumer/family input in the transition process (IFSP/IEP).

Objective 5: To document adult outcomes as designed in the transition goals.

Objective 6: To cooperate and coordinate the delivery of services with other related State, Federal, and Local agencies.

Objective 7: To support a parent-to-parent outreach network.

ACTIVITIES

Staff Development Trainings

Staff Development Trainings conducted by the Transition Planning Consultant

Description of Activity:

The Transition Planning Consultant conducted 8 staff development trainings on a variety of topics for schools and adult service agencies that provide services to individuals with deaf-blindness. The following is a brief description of each training, the number of participants, etc.:

1. 28 October 1994
Title: **Introduction to Deaf-Blindness**
Presenters: Cathi O'Brien and Larry Rhodes
Participants: Direct service staff from the Saint Louis ARC (Association for Retarded Citizens)
Number of participants: 16

The Saint Louis ARC is a large agency with several sites located throughout the Metropolitan Saint Louis Area. This agency provides a variety of services (day programs, job development and supported employment, residential, etc.) to youth and adults with developmental disabilities. This agency has recently begun serving individuals with deaf-blindness and has made a commitment to expand its services to provide appropriate services to deaf-blind consumers. The agency has not only increased the number of deaf-blind consumers to whom it is providing services, but the agency has created its own, internal, resource team.

This workshop was provided as an initial training to that resource team. It was open to any interested individual in the agency.

A copy of the agency's summary of the training evaluations can be found in **Appendix A** of this report.

2. 25, 26, 27 January 1995
Title: **Saint Louis ARC Deaf-Blind Core Team Training, Part I**
Presenters: Wayne Elrod and Larry Rhodes
Participants: Members of a core team (both direct service and administrative staff) of an adult services agency in Saint Louis that is expanding its services to serve a greater number of deaf-blind consumers
Number of participants: 10

The Saint Louis ARC (Association of Retarded Citizens) is a large agency with several program sites throughout the Metropolitan Saint Louis Area. This agency provides a variety of services (day programs, job development and supported employment, residential, etc.) to youth and adults with developmental disabilities. This agency has recently begun serving individuals with deaf-blindness and has made a commitment to expand its services to provide appropriate services to deaf-blind consumers. The agency has not only increased the number of deaf-blind consumers to whom it is providing services, but the agency has created its own, internal, resource team. This training was the first of two three-day trainings on issues related to deaf-blindness. The workshop focused on vision loss, hearing loss, and then how the combination of the two losses affects individuals.

For a copy of the evaluation summary, please see **Appendix A** of this report.

3. 17 March 1995
Title: **Assessing the Visual Functioning of Children Who Have Multiple Disabilities and/or Are Hard to Assess**
Presenter: Larry Rhodes
Participants: Teachers, paraprofessionals, therapists (OT, PT, Speech), and social workers in the Deaf-Blind/Multihandicapped Program in the Kansas City (Missouri) Public Schools
Number of participants: 26

The Kansas City Schools' Deaf-Blind Program provides educational services to children and youth with deaf-blindness. This program receives special funds from the Missouri State Department of Elementary and Secondary Education to provide services for children with deaf-blindness from several LEAs throughout the Metropolitan Kansas City, Missouri area. At the time of this workshop, the program was providing services to 29 students, 12 of whom were transition age (age 14 - 22 years).

Only three participants had any background in vision (one had VI certification, one had O&M certification, and the third had Deaf-Blind certification). The purpose of this workshop was to provide the participants with strategies that can be used when assessing the visual functioning of the students in the Kansas City Schools' Deaf-Blind Program.

This workshop was coordinated along with several others by the Kansas City Schools' Professional Development Academy. The School System distributed and collected evaluations for this workshop. This consultant has requested a copy of the summary of the evaluations, but to date, one has not been received from the Kansas City Schools.

4. 3, 4, 5 May 1995
Title: **Saint Louis ARC Deaf-Blind Core Team Training, Part II**
Presenters: Cathi O'Brien and Larry Rhodes
Participants: Members of a core team (both direct service and administrative staff) of an

adult services agency in Saint Louis that is expanding its services to serve a greater number of deaf-blind consumers

Number of Participants: 14

This was the second and final three-day training for a resource (core) team that was established by the Saint Louis ARC (Association of Retarded Citizens). The purpose of this core team is to provide initial technical assistance to the entire agency as the agency continues to expand services to deaf-blind consumers. The topics covered during this three day training were: Assessing and Modifying the Environment to Enhance Visual Functioning; In Depth Examination of the Four Basic Types of Deaf-Blindness, Their Causes, and Their Implications for Habilitation; and, Introduction to Deaf-Blind Communication.

A summary of the evaluations was not forwarded by the agency, so a copy is not included with this report.

The participants developed an Action Plan at the end of this workshop. It called for a formal establishment of the resource team. The Transition Planning Consultant met with the participants of the resource team two more times to facilitate the development of a Values and Mission Statement, a Plan (with both long and short term goals), and a Mandate.

5. 22 May 1995

Title: **Introduction to Deaf-Blindness**

Presenters: Larry Rhodes and Cathi O'Brien

Participants: Direct service and supervisory staff of four residential/day habilitation centers which are part of the Missouri Department of Mental Health; direct service and supervisory staff of a private not-for-profit agency that provides supported living care; and, a state school for severely handicapped children.

Number of participants: 26 from 6 different agencies

Number of consumers and families affected by this training: 5

This is the first time the staff from 5 of the agencies (all of which are state agencies) have ever attended any training related to deaf-blindness. The direct and supervisory staff of four deaf-blind consumers have never had any training in this topic area until this time. These same four agencies are providing services to deaf-blind consumers for the first time and will provide services to additional deaf-blind consumers in the future.

This workshop provided staff with a foundation/awareness of deaf-blindness. Participants now have a basis upon which to build increasing skills in working with deaf-blind consumers and their families.

A copy of the Training/Workshop Attendance Sheets as well as a copy of the Summary of Workshop/Training Evaluations can be found in **Appendix A** of this report.

6. 11 July 1995
Title: **The Structure & Functioning of the Visual System; Reading Eye Reports**
Presenter: Larry Rhodes
Participants: Teachers participating in the Indiana Deaf-Blind Services Project 1995 Summer Institute.
Number of participants: 13

The participants in this Institute are participating in the Indiana Deaf-Blind Services Mentor Project.

The purpose of this workshop in the Institute was to provide the participants with an overview of the structure of the visual system, how it functions, and what can go wrong with it. The workshop also provided the participants with strategies and tools needed to read eye reports.

The participation of the Transition Planning Consultant in this Institute is the result of collaboration between the Indiana 307.11 Project, the Missouri 307.11 Project, and TRACES.

A summary of the participants evaluation for this workshop as well as the results of a pre- and post-test taken by the participants can be found in **Appendix A** of this report.

7. 10 August 1995
Title: **Introduction to Deaf-Blindness**
Presenter: Larry Rhodes
Participants: Parents of transition age consumers with deaf-blindness, members of the Saint Joseph/Region 1 Deaf-Blind Task Force, and direct service staff of agencies providing services/supports to consumers with deaf-blindness and their families.
Number of participants: 10

The Saint Joseph/Region 1 Deaf-Blind Task Force was formed nearly a year and one-half prior to this training. Other than the parents of two transition age consumers, the other members of the Task Force have minimal to no knowledge/experience with deaf-blindness. The direct service staff who attended this workshop also had no background in issues related to deaf-blindness.

The purpose of the workshop was to provide awareness of vision and hearing losses and how these two losses - particularly when they occur in conjunction with each other - affect an individual's development and functioning. This workshop also provided the participants with a foundation for future, expanded training in specific topic areas relating to deaf-blindness.

A copy of the summary of the participants' evaluations for this training can be found in **Appendix A** of this report. For a copy of the training materials developed and used for this training, please see **Appendix B** of this report.

8. 11 September 1995
Title: **Developing Communication for Children and Adults with Deaf-Blindness - Module #1**
Presenter: Larry Rhodes
Participants: The parents and direct service staff of two transition age individuals with deaf-blindness (Agencies: Progressive Community Services and Unity Home, Inc.)
Number of participants: 5

This staff training was the first of a series of on-going trainings/technical assistance to the direct service staff of two transition age deaf-blind consumers. Both consumers were in programs with a 1:1 staff-consumer ratio. The staff worked for two agencies that are members of the Saint Joseph/Region 1 Deaf-Blind Task Force. None of the staff members had any training in working with deaf-blind consumers. Neither consumer had a consistent, formalized linguistic symbols system in operation; their methods of communication included only natural body gestures, behaviors, and very few tangible symbols.

A copy of the summary of the participants' evaluations for this training can be found in **Appendix A** of this report. For a copy of the training materials developed and used for this training, please see **Appendix B** of this report.

Impact of Activity:

An historical problem in designing and implementing effective transition plans for deaf-blind youth is securing services from State and private adult service agencies which are willing to both provide services to deaf-blind individuals and develop communication and other specialized skills in their direct service staffs that needed to provide effective services to these deaf-blind individuals. Since the formation of the various local deaf-blind task forces across the state, a number of these State and private agencies have been willing to initiate services and/or improve services provided to deaf-blind consumers and their families.

At the time of the above trainings, these education and adult service agencies were providing a variety of services to approximately 28 - 30 transition age youth and nearly the same amount of adult deaf-blind consumers. In addition, the trainings also affected the direct service staff of approximately 20 deaf-blind students between the ages of 3 and 14 years.

As the educational and adult service agencies received training on issues related to deaf-blindness, they have found themselves to be in a better position to offer and/or improve services to deaf-blind youth who are transitioning from school into their communities. One example of this happening is the establishment of a resource/core team of trained individuals in an adult service agency in Saint Louis (The Saint Louis ARC). As the result of initial training in deaf-blind issues during the 1993-1994 project year, that agency has decided to establish this resource team to provide initial technical assistance on deaf-blind issues throughout this agency. To train this team, the agency requested three sets of trainings in deaf-blindness (described above).

Two agencies in Saint Joseph (Progressive Community Services and Unity Home, Inc.) are currently collaboratively providing an independent supported living/day program to two transition age youth. The direct service and supervisory staffs of these two agencies have been receiving training in deaf-blind issues during the past project year. This training has been in the form of workshops (described above) and in on-going technical assistance/training. This has resulted in the creation of a "Deaf-Blind Daytimer" (anticipation calendar) for one of the youth (the other youth's calendar is being designed). The direct service teams of both youth are developing and implementing a plan to create a consistent communication system for both. These systems are using concrete/tangible symbols. This is the first time either youth have used any formal type of communication system other than their behaviors.

Since the second of a two part training on assessing the visual functioning of students with multiple disabilities, the staff of the Kansas City Schools' Deaf-Blind Program have begun to develop a plan to assess the visual functioning of the students in that program. The resource teacher for the Kansas City Schools' Deaf-Blind Program will enroll in a graduate level low vision class at the University of Missouri - Saint Louis. The class focuses on conducting visual assessments and writing recommendations for IEPs that provide for teaching of visual skills to students with vision loss.

As education and adult service agencies receive training in deaf-blind related issues, they have been contacting the Transition Planning Consultant and/or their respective Deaf-Blind Task Forces to request technical assistance.

This activity addresses the following objectives of the 307.11 grant: #2, #3, and #5

Staff Development Trainings Coordinated by the Transition Planning Consultant

Description of Activity:

The Transition Planning Consultant coordinated the following workshop hosted jointly by the Missouri 307.11 Project and the Saint Louis Deaf-Blind Task Force:

10 - 11 May 1995
Title: **Orientation and Mobility for Individuals with Dual Sensory Losses**
Presenter: Joan Houghton, MEd, - Helen Keller National Center - Technical Assistance Center
Participants: Teachers, teachers' aides, principal of a deaf-blind/multi-handicapped educational program, job coaches, and other direct service and supervisory staff of adult service and educational agencies in the Metropolitan Saint Louis Area that

provide services to Deaf-Blind consumers and their families.
Number of Participants: 28

This two-day workshop was co-hosted by the Missouri 307.11 Project and the Saint Louis Deaf-Blind Task Force. Several adult service and educational agencies that participate on the Saint Louis Deaf-Blind Task Force had expressed the need for such a workshop. There are very few certified, university trained O&M specialists in the State of Missouri and virtually none have extensive experience in providing O&M training to deaf-blind consumers. The purpose of this workshop was to provide some basic sighted guide and other none-cane skills (with modifications for deaf-blind consumers with special needs) to direct service staff who, in turn, can use these skills when working with deaf-blind consumers.

A copy of the summary of the evaluation forms can be found in **Appendix A** of this report.

Impact of Activity:

See *Impact of Activity* under **Staff Development Trainings conducted by the Transition Planning Consultant** above.

Third California TEAM Summer Institute

Description of Activity:

The Transition Planning Consultant presented at and attended the third and final Transdisciplinary Education Assessment Model (TEAM) Summer Institute facilitated by the California Deaf-Blind Services (California's 307.11 Project) 6 - 8 July 1995, in Newport Beach, California. This was the third and final follow-up workshop for professionals who have established local transdisciplinary teams to provide assessments and to develop instructional strategies for children and students with deaf-blindness. The Missouri 307.11 Project's Transition Planning Consultant reviewed the teams' past year's activities, provided feedback, and presented more information regarding vision/vision and transdisciplinary teaming when conducting assessments.

Impact of Activity:

The transdisciplinary approach to assessment of functioning and educational needs of a student with deaf-blindness leads to the development of more realistic and person-centered education (and, hopefully, transition) goals and strategies.

In the past three years, information from the California TEAM Model has been shared with education and adult service agencies collaborating with the Missouri 307.11 Project. This has resulted in establishment of a transdisciplinary resource/core team in one adult service agency in St. Louis (The Saint Louis ARC). Two education programs in the Greater Kansas City Area (the Kansas City Schools' Deaf-Blind Program and the Blue Springs Schools' Special Services Program) are considering developing at least one transdisciplinary team. The Missouri 307.11 Project staff are working with the California Deaf-Blind Services to bring staff from their project to Missouri to present the TEAM Model to the programs in Kansas City. This meeting is being planned for early Spring 1996.

This activity addresses the following objectives in the 307.11 grant: #2, #3, #4, and #6.

Product Development

Development of Parent Handbook on Transition

The Future is Around the Corner!

Description of Activity:

During the fall of 1993, the Missouri 307.11 Project's Curriculum Specialist and Transition Planning Specialist completed a transition planning manual for parents of youth with disabilities. The manual was then reviewed and field tested for the next year by the Missouri Center for Innovations in Special Education (CISE) at the University of Missouri - Columbia for the next several months.

This planning manual, *The Future is Around the Corner!*, was finalized, printed, and distributed in the late spring of 1995.

This manual provides parents with information that will help them think about the future for their children who have disabilities and for themselves.

Impact of Activity:

CISE has distributed several hundred copies of this handbook throughout the state. It is being used as a resource by parents. No other information regarding impact is available at this time from CISE.

A copy of this handbook can be found in **Appendix B** of this report.

This activity addresses the following objectives in the 307.11 grant: #3, #4, and #5.

Development of Deaf-Blind Training Materials

Description of Activity:

During this past grant year, the Missouri 307.11 Project Staff aggressively began the implementation of a decision made the previous grant year to establish a "train-the-trainer" model for increasing staff development training for education and adult service agencies throughout the state. This plan initially utilizes resources available on both a state and local level.

Training Material: *Introduction to Deaf-Blindness Workshop*

In the summer of 1994, the Missouri State Department of Mental Health - Bureau of Deaf Service's (BDS) Eastern (Missouri) Coordinator and the Missouri 307.11 Project's Transition Planning Consultant met to initiate this project. The first activity planned was the writing of a training manual that could be used as a day-long, experiential workshop that would provide an introduction to deaf-blindness.

After the first draft of this training was completed, the BDS Coordinator and the Transition Planning Consultant set up a workshop to field test this training manual. The BDS Coordinator and the Transition Planning Consultant met with staff from the Saint Louis ARC (Association for Retarded Citizens) to plan a series of trainings for a newly established resource/core team. The training manual was field tested with that team on Friday, 28 October 1994. The workshop was again field tested on 22 May 1995. After these two workshops, the content and format of the workshop was modified and again field tested in August 1995. It is scheduled to be field tested again twice in December 1995.

Once the training materials have been finalized, interested individuals from various education and adult service agencies across the state of Missouri will be trained in facilitating the workshop.

What remains to be done with this training material is the re-writing of the vision and hearing sections (making them shorter and not using SKI*HI materials) and the drawing of illustrations and the field testing of this final. This is scheduled for the 1995-1996 grant year as a technical assistance activity from TRACES.

A copy of the current draft of this training material (*Introduction to Deaf-Blindness Workshop*) can be found in **Appendix B** of this report.

Training Material: *Developing Communication for Children and Adults with Deaf-Blindness*

There is a serious need for professionals (both in education and in adult service agencies) to be trained in the various issues related to deaf-blindness. The most critical issue is communication which, in turn, affects anticipation, motivation, and learning for a deaf-blind consumer. This is being addressed with infants, toddlers, and preschoolers in the state of Missouri through a state-wide family centered, home-based early intervention program (Mo-SPIN) which is a collaborative effort of the State's 307.11 Project and the Outreach Division of the Missouri School for the Blind. This early intervention program teaches family members and other care givers using the INSITE Curriculum developed by the SKI*HI Institute at Utah State University, Logan, Utah. Through various forms of technical assistance provided by the State's 307.11 Project, classroom teachers are trained in deaf-blind communication issues. When deaf-blind youth transition from school into their communities, they often receive services from agencies whose staff have no knowledge in the area communication. Many of their youth often revert back to pre- and/or non-symbolic forms of communication. In addition, many youth may transition from school to their communities only using pre- and/or non-symbolic communication and need support to develop a symbolic communication system. Their direct service staffs do not have the skills required to continue that development.

This need has been shared repeatedly with the various local deaf-blind task forces across the state. The staff of the Missouri 307.11 Project decided to develop a series of training using a modular format to provide direct service staff (education and adult service) with the skills required to develop/encourage communication skills in deaf-blind consumers. Eventually, educators and adult service staff will be trained to replicate these trainings in their areas of the state.

In preparation, the Transition Planning Consultant participated in a week long professional training seminar, "Communication with Learners Who Are Deaf-Blind", in July, 1995. This training was sponsored by the Perkins National Deaf-Blind Training Project and Texas Tech in collaboration with the 307.11 Projects across the country.

The Transition Planning Consultant developed an outline for the series of modules and then wrote the first module. This module was field tested in September 1995.

A final outline for the series will be completed early in 1996 and at least two more modules will be written and field tested by the end of summer 1996. Final drafts of the first three modules are scheduled to be completed by the end of September 1996. As each module is completed, the Transition Planning Consultant will train interested professionals across the state to become local trainers. The completion of these first three modules is now a technical assistance goal of TRACES.

For a copy of the first draft of module #1, please see **Appendix B** in this report.

Impact of Activity:

The establishment and development of three local deaf-blind task forces across the state have had a tremendous impact in establishing and improving services to deaf-blind consumers and their families (please see **Missouri Deaf-Blind Task Forces** below). Participation on these local task forces by various education and adult service agencies has created an awareness in these agencies for the need of establishing and/or improving education, rehabilitation, employment, and other critical services for deaf-blind consumers and their families. Several of these agencies assessed the quality and effectiveness of their respective programs. Many realized that they were approaching deaf-blindness solely from the viewpoint of mental retardation without considering impact that the dual sensory losses (vision and hearing) have on the development of concepts, communication, and so on.

Not only has initiating the development of these training materials provided hands-on, practical training for direct service staff, but it will also assist in the larger plan building local capacity in many areas of the state. As professionals in the more heavily populated areas of the state (Metropolitan Saint Louis, Metropolitan Kansas City, Saint Joseph - and now Columbia and Jefferson City) are able to conduct certain staff development trainings locally, this allows the staff of the 307.11 Project to conduct staff development trainings in other areas of the state. On-going locally conducted training on basic issues related to deaf-blindness, has resulted in a reduced need to secure the Helen Keller National Center's National Training Team to repeatedly conduct similar trainings in the state. This has been a tremendous saving to the State's 307.11 Project as well as to the education and adult service agencies participating on the various task forces.

This activity addresses the following objectives in the 307.11 grant: #2, #3, and #6

Personal Futures Planning/Essential Lifestyles Planning

Facilitating Personal Futures Plans/Essential Lifestyles Plans

Description and Outcomes of Activity:

A. The Transition Planning Consultant continues to facilitate the implementation of the Personal Futures Plan (PFP) of one transition age youth. This Plan was initiated last year. During the summer of 1995, the parents of this youth decided to work with the Transition Planning Consultant, an adult service agency, and the youth's case manager from the State's Department of Mental Health in creating a "wrap around" day program for the youth that would be developmental rather than just adult day care. Due to the need of setting up such a program in the matter of a few weeks, the youth's Circle of Support decided to have the Transition Planning Consultant facilitate the creation of an Essential Lifestyles Plan (ELP) for this youth. The reason for the sudden shift from a PFP to an ELP was so that all the information gathered in the process of developing and implementing the youths PFP could be quickly reviewed, summarized, and then placed in a format that could be easily used in developing a program specifically for that youth. *Outcome:* Through intensive collaboration between the case manager from the Dept of Mental Health and the adult service agency, initial funding was secured. The ELP resulted in the developing of an Individual Habilitation Plan that is beginning to meet that youth's various needs. The youth's parents have decided to decline services from the LEA at this time (but not yet formally graduate their son) with the intention of securing additional funding so that the current program can be expanded until it is truly more "wrap-around" in nature. The Essential Lifetyles Plan continues to be implemented.

B. In May, 1995, the Transition Planning Consultant was requested by the Missouri School for the Deaf to provide consultation/support as the school begins to address the needs of a transition age student who had recently experienced a significant reduction in her vision. The Transition Planning Consultant has been several times with the student's parent and IEP team. The information regarding Personal Future Planning was shared with the parent and IEP team. In the fall of 1995, the parent requested that the Transition Planning Consultant facilitate the development and implementation of a PFP for her daughter. The date for the first PFP meeting has been set for January 1996.

C. In November 1993, the Transition Planning Consultant facilitated a series of PFP meetings that developed and implemented a Personal Futures Plan for a transition age youth who graduated in June 1994. The Plan has been fully implemented.

Outcome: At the time the PFP process was started, there existed no program in that youth's community that could address his developmental needs. His PFP drove the development and implementation of his IHP (Individual Habilitation Plan). His Personal Futures Plan was assisted in its implementation through a collaborative effort of agencies participating on the deaf-blind task force serving his area of the state. The result was the creation of a special one-on-one program for this youth which is now meeting his developmental needs. The youth's parents are very satisfied with the program that was developed.

Trainer of Other Personal Futures Planning Facilitators:

Description of Activity:

There are nearly eighty transition age deaf-blind youth in Missouri (approximately 30 of these youth reside in the six counties covered by the Greater Kansas City Deaf-Blind Task Force). Not many individuals in Missouri who are skilled PFP facilitators have been identified in the state. Most of those identified are already facilitating PFPs. There is a need to train more. In January and February of 1995, the Missouri 307.11 Project's Family Support Coordinator and Transition Planning Consultant were trained by Michael McCarthy to train others to become facilitators in the Personal Futures Planning process.

Impact of Activity:

To date, neither 307.11 staff member has been asked to conduct a workshop to train additional facilitators in the PFP process. The Greater Kansas City Deaf-Blind Task Force originally had considered hosting a training for new facilitators in October 1995, but due to other activities, this training was not held.

Parent Workshops

"Best Practices and Real Life Issues: A National Workshop for Parents of Transition-Age Young Adults Who Are Deaf-Blind"

Description of Activity:

This national workshop was sponsored by the Helen Keller National Center - Technical Assistance Center and was conducted 27 - 29 October 1994, in Saint Louis, Missouri. The Transition Planning Consultant coordinated with the staff of the Helen Keller National Center - Technical Assistance Center (HKNC-TAC) in selecting parents from Missouri to attend this national workshop. HKNC-TAC sponsored two of the participants from Missouri while the Missouri 307.11 Project provided financial assistance to the other parents who requested it. Nine parents from Missouri attended the conference. Three of the parents are also members of Deaf-Blind Task Forces in the state (the State Deaf-Blind Task Force, the Greater Kansas City Deaf-Blind Task Force, and the Saint Louis Deaf-Blind Task Force).

Impact of Activity:

This workshop gave the Transition Planning Consultant an opportunity to meet several of these parents face-to-face for the first time. Two parents had recently moved into the state and this was their first contact with the state 307.11 Project.

For the three parents who are members of various Deaf-Blind Task Forces in the state, this provided them with an opportunity to learn more about best practices in several areas relating to deaf-blindness. This information was then taken back and used on their respective Task Forces. In addition, one of these same parents is a regional director of a state-wide parents advocacy group.

This activity addresses the following objectives in the 307.11 grant: #3 and #4.

Technical Assistance to Direct Service Teams

Coordinating Technical Assistance from the Helen Keller National Center - Technical Assistance Center.

Description of Activity/Outcomes:

The Transition Planning Consultant coordinated technical assistance provided by Joan Houghton from the Helen Keller National Center - Technical Assistance Center to several direct service teams in Missouri. Following, is a summary of the technical assistance with the related outcomes.

1. Youth's name: **NK**
   Community: **Saint Louis**

Type of technical assistance: **review of records, consultation with team members, observations**
Date(s) of technical assistance: **26 May 1996**

Description of Technical Assistance Activity: The purpose of the technical assistance was to address some concerns of the youth's parents. The youth's program consisted primarily of positioning, eating, and toileting. His mother wanted some technical assistance to help the school increase his communication skills and to expand his community based instruction (and make the community based instruction more meaningful to him). Joan Houghton interviewed the youth's mother, reviewed the youth's school records, and met with the youth's classroom teacher and other direct service staff. Ms. Houghton also observed the interaction between the youth and his classroom staff.

A series of recommendations were written and submitted to the parents and the youth's teacher. These recommendations addressed: expanding the youth's anticipation calendar; expanding the use of tangible symbols, cues, and some signs; and, strategies to expand his opportunities for community based instruction.

Outcome: Due to disagreements with their son's IEP team, the youth's parents have declined services from the LEA - but they have not officially graduated him. Instead, the parents, in collaboration with the State Department of Mental Health and several local adult service agencies that participate on the Saint Louis Deaf-Blind Task Force, have created a day program that, the parents and others believe, better addresses the youth's developmental needs.

The recommendations provided by Joan Houghton have been incorporated into the youth's Individual Habilitation Plan (IHP) and are being implemented with a great deal of success. The youth's parents are happy with the results they have seen to date. Since this new program is one-on-one with the youth, he is being provided with greater opportunities to interact with people. His direct service staff have expanded his choices in several areas. They have expanded the use of his anticipation calendar. More object representatives are being used with success with this youth.

For additional information regarding technical assistance provided to this direct service team, please see the next section of this report, **Technical Assistance Provided to Direct Service Teams by the Missouri 307.11 Project's Transition Planning Consultant**, below.

2. Youth's name: **JH**
Community: **Saint Joseph**
Type of technical assistance: **consultation with team members and observations**
Dates of technical assistance: **13 January 1995, 5 June 1995**

Description of Technical Assistance Activity: The purpose of this technical assistance was to provide his Individual Habililtation Plan Team (IHP) with recommendations to be incorporated into the goals of the youth's IHP along with suggestions of activities that can be used to reach these goals. Several individuals - including the youths parents and direct service staff - were concerned about the appropriateness of the program being offered by the adult service agency contracted by the State Department of Mental Health to work with JH.

The youth was not feeling well the day of the visit by Joan Houghton and the Missouri 307.11 Project's Transition Planning Consultant. Information regarding the youth, his program, etc., were provided by his parents, his instructors, and the director of the adult service agency providing the program. Several programmatic issues were identified: funding for equipment; appropriate training for the direct service staff; transportation; the physical facilities; and so on.

The consultant provided several detailed recommendations for the service agency to address most of the concerns voiced during the meeting. Several programmatic recommendations with solid examples of how to implement the recommendations were also provided. Finally an Action Plan was developed for JH's family and team.

Outcome: Due to irreconcilable differences between the service agency and JH's parents, JH's parents had his program and staff move to another service agency. The Transition Planning Consultant then met with JH's parents, direct care staff, case manager from the Dept of Mental Health, and supervisor of the new service agency to develop a new Action Plan based upon the recommendations provided by Joan Houghton. The recommendations made by Joan Houghton were incorporated into a new IHP for JH. Needed equipment was finally ordered. Transportation issues were resolved. A plan for training JH's direct service staff was developed and partially implemented. This significant improvement in JH's overall program since transferring his program to the new service agency was noticed and documented by Joan Houghton during a subsequent on-site visit to provide technical assistance (see next paragraph).

Description of Technical Assistance Activity: Due to problems that resulted from the transferring of JH's program from one service agency to another as well as due to direct service staff turnover, Joan Houghton did a follow-up on-site technical assistance visit to JH's program and team. JH was feeling well the day of this visit and Joan was able to observe his staff working with him. (NOTE: both JH's old staff who were leaving shortly to new jobs as well as his new replacement staff were available the day of Joan's follow-up visit.) Joan noted that JH's old staff were effective in conveying to JH's new staff the teaching strategies appropriate for JH as well as other critical information needed to work with him. Joan provided additional recommendations that expanded upon those given the previous January. They included the need for additional training in issues related to deaf-blindness for JH's staff, the need to secure OT and/or PT as well Speech Language services, and additional equipment for communication purposes.

The Missouri 307.11 Transition Planning Consultant subsequently met with JH's IHP team to develop an action plan for implemention of the recommendations.

Outcome: JH's anticipation calendar is now up and running. JH has expanded his repertoire of expressive cues. JH has an increased amount of activity in the community. Needed equipment is continuously being purchased as it is identified.

For additional information regarding technical assistance provided to this direct service team, please see the next section of this report, **Technical Assistance Provided to Direct Service Teams by the Missouri 307.11 Project's Transition Planning Consultant**, below.

3. Youth's name: **JC**
Community: **Kansas City**
Type of technical assistance: **consultation with teaching staff, group home staff, consultation with other consultants, and observations**
Date of technical assistance: **10 January 1995**

Description of Technical Assistance Activity: Joan Houghton and the Missouri 307.11 Transition Planning Consultant were requested to provide technical assistance to the classroom staff of a 16 year old youth, JC, who had in the days just prior to Joan's visit began physically assaulting the classroom teacher. No education or medical records were available to be reviewed by Joan or the 307.11 staff at the time of the on-site visit. A meeting was called with the classroom staff, direct service and supervisory staff of JC's group home, and the director of the Kansas City Schools' Deaf-Blind Program. It became very clear to both consultants early on that there were severe problems of communication between the group home and classroom staffs. There were also problems in using the appropriate communication system with JC.

JC has a severe hearing impairment and can only detect environmental sounds with amplification. She can hear speech, but she is unable to discriminate speech. JC uses signs and pencil/paper effectively to communicate. The staff at JC's group home believed that JC could, in fact, understand speech and refused to use any signs with her at all. Very few of JC's classroom staff have any knowledge of sign and their vocabulary is very limited.

The consultants asked the teaching staff and the group home staff if they would be willing to have a behavioral consultant provide services. This service would be coordinated by HKNC-TAC and the Missouri 307.11 Project and funded by HKNC-TAC. Both groups agreed. A consultant, Michael McCarthy, was contacted and agreed to meet with both groups to address JC's behavior. A contingency behavioral plan was developed by Joan and the 307.11 staff to be used in the classroom until Mike McCarthy could meet with the classroom staff and work out a plan. This plan was based solely upon the staff's report and input, and from the observations made Joan during her visit to the classroom.

The 307.11 staff developed an experience story to depict the contingency behavior plan to JC. The plan was conveyed to JC through the use of signs (the 307.11 staff is fluent in ASL and MCE), the visual representations on the experience story, and through role-playing the plan. This information was reviewed with JC until she could expressively communicate every step of the sequence to the consultants. She was even able to describe the consequences of both appropriate and inappropriate behaviors.

It was emphatically recommended to the group home that behavior management policy be developed and implemented.

It was also strongly recommended to both staffs that the appropriate modes of communication (primarily sign, secondarily written words) be used with JC at all times.

Outcome: The contingency behavior plan was not followed properly by JC's classroom staff. The classroom staff did not sign consistently to JC. The group home never developed a behavior policy. The group home continued to insist that JC could lip ready accurately everything that was said and/or had enough residual hearing to understand speech without the use of amplification. Furthermore, the group home refused to work with Mike McCarthy when he arrived to provide the requested technical assistance.

Within a week of Joan's and the 307.11 Project's Transition Planning Consultant's visit, JC struck her teacher again. Continued outburst eventually resulted in JC's expulsion from school. She received homebound educational services from her LEA. Repeated violent outbursts in the home ultimately led to JC being sent to a state hospital.

For additional information regarding technical assistance provided to this direct service team, please see the next section of this report, **Technical Assistance Provided to Direct Service Teams by the Missouri 307.11 Project's Transition Planning Consultant**, below.

4.. Youth's name: **LC**
Community: **Blue Springs**
Type of technical assistance: **consultation with teaching staff, review of available records, and observations**
Date of technical assistance: **11 January 1995**

Description of Technical Assistance Activity: Joan Houghton and the Missouri 307.11 Projects' Transition Planning Consultant met with LC's classroom teacher and Speech Language Pathologist. LC was diagnosed the previous year with Batten Syndrome (reported to be a degenerative condition). LC's parents are divorced and they have joint legal custody of LC. LC spends part of a school year in Blue Springs and part of the year in Tennessee.

Several recommendations were made regarding communicating with LC. Increasing activities that would provide LC with tactile feedback was recommended. To help LC identify different staff at her program, the use of object reps for each staff person was also recommended. Background noise needed to be minimized. An anticipation calendar was recommended.

Outcome: Many of the recommendations provided by the consultants were implemented. The results are mixed however due in part to LC's degenerative condition and in part to her splitting the school year between two programs in two different states.

These activities address the following objectives in the 307.11 grant: #2, #3, and #6.

Technical Assistance Provided to Direct Service Teams by the Missouri 307.11 Project's Transition Planning Consultant

Description of Activities/Outcomes:

The Transition Planning Consultant provided technical assistance to several direct service teams in Missouri. Following, is a summary of the technical assistance with the related outcomes.

1. Youth's name: **NK**
Community: **Saint Louis**
Type of technical assistance: **review of records, consultation with team members, training direct service staff, conducting transition planning meetings, and observations**
Date(s) of technical assistance: **22 November 1994; 20 January 1995; 10 February 1995; 20 March 1995; 7, 10, and 12 April 1995; 8, 18, 22, and 31 May 1995; 7 June 1995; 16 August 1995; and, 20 September 1995**

Description of Technical Assistance Activities: The Transition Planning Consultant provided a wide range of technical assistance support to the education and adult agencies providing support to NK and his family. A wide range of technical assistance was also provided directly to NK's family. Some of these activities were: facilitating the development and implementation of a Personal Futures Plan (PFP); attending IEP meetings; coordinating additional technical assistance from the Helen Keller National Center - Technical Assistance Center; assisting the family in writing a proposed position description for an intervenor; facilitating the development and implementation of an Essential Lifestyles Plan (ELP) when NK's parents decided to decline services from their LEA; attending IHP meetings, assisting in the development of IHP's that incorporate the information gathered during the facilitation of NK's PFP and ELP; providing training to NK's direct service staff on communication and other issues related to deaf-blindness, etc.

In addition, the Transition Planning Consultant nominated one of NK's parents to join the Saint Louis Deaf-Blind Task Force. The parent now attends virtually every meeting of the Task Force. In addition, the Transition Planning Consultant arranged for this parent to participate in the national parent workshop sponsored by the Helen Keller National Center in Saint Louis in October 1994. (For more information about this workshop, see **"Best Practices and Real Life Issues: A National Workshop for Parents of Transition-Age Young Adults Who Are Deaf-Blind"** above.)

Outcomes: When it became clear to NK's parents that they could not get the type of services they wished for their son from the LEA without going through due process, the parents collaborated with the Saint Louis Deaf-Blind Task Force, the Transition Planning Consultant, the State Department of Mental Health, and several adult service agencies to design and fund a one-on-one program for NK. This program has gradually expanded 23 hours per week. It is planned that the program will expand to more than 40 hours per week as additional funding is secured. NK's IHP (Individual Habilitation Plan) incorporates the information gleaned in the PFP and ELP processes; his one-on-one program is meeting NK's developmental needs. NK's parents are further collaborating with the Saint Louis Deaf-Blind Task Force to identify systems barriers and solutions to these barriers. Three members of NK's direct service team will be participating in a special transition planning conference sponsored by the Helen Keller National Center - Technical Assistance Center to be held in April 1996, in Phoenix, AZ.

For additional information regarding technical assistance provided to NK through the Missouri 307.11 Project, please see the previous section to this report, **Coordinating Technical Assistance from the Helen Keller National Center - Technical Assistance Center**.

2. Youth's name: **JH**
Community: **Saint Joseph**
Type of technical assistance: **review of records, consultation with team members, training direct service staff, conducting transition planning meetings, and observations**
Dates of technical assistance: **7 November 1994; 15 December 1994; 10, 12 January 1995; 14, 16 February 1995; 14, 1 March 1995; 17, 18 April 1995; 9 May 1995; 8 August 1995; and, 11 September 1995**

Description of Technical Assistance Activities: The Transition Planning Consultant provided a wide range of technical assistance support to the education and adult agencies providing support to JH and his family. Some of these activities were: facilitating the development and implementation of a Personal Futures Plan (PFP); attending IHP (Individual Habilitation Plan) meetings; assisting in the development of IHP's that incorporate the information gathered during the facilitation of JH's PFP and from previous technical assistance visits; coordinating additional technical assistance from the Helen Keller National Center - Technical Assistance Center; providing training to NK's direct service staff on communication and other issues related to deaf-blindness, etc.

In addition, JH's mother was one of two parents of youth with deaf-blindness who were instrumental in the creation of the Saint Joseph/Region 1 Deaf-Blind Task Force. JH's mother is still a very active member of the Task Force.

Outcomes: The original and subsequent IHPs developed for JH included many components identified in JH's PFP. However, due to the original service agency's not implementing the IHP effectively, JH's parents requested that JH's program be transferred to another adult service agency. A new IHP was developed and implemented. JH is now using a "Deaf-Blind Daytimer" (anticipation calendar) with growing success. JH's revised IHP has increased the frequency of his participating in the community.

For additional information regarding technical assistance provided to JH through the Missouri 307.11 Project, please see the previous section to this report, **Coordinating Technical Assistance from the Helen Keller National Center - Technical Assistance Center**.

3. Youth's name: **JC**
Community: **Kansas City**
Type of technical assistance: **review of records, consultation with teaching staff, group home staff, consultation with other consultants, performing an assessment of JC's visual functioning/skills, and observations**
Dates of technical assistance: **10 January 1995; 11 January 1995; 13 February 1995; 22 February 1995; 30 January 1995; and, 29 March 1995**

Description of Technical Assistance Activity: JC was a 16 year old woman with the diagnosis of Congenital Rubella Syndrome. She was a ward of the state and was placed in a group home. Her LEA was a suburban Kansas City, MO school district but her educational placement was in the Kansas City School's Deaf-Blind Program (through a contact between the LEA and the Kansas City Schools). JC had a mild vision loss even when wearing her corrective lenses. She had a bilateral moderately-severe mixed hearing loss.

Shortly after the Kansas City Schools' Deaf-Blind Program requested technical assistance in the areas of communication and an assessment of JC's vision, JC began to assault her classroom teacher (and then later physically dismantle the classroom itself) for no apparant reason. Technical assistance was requested and received from the Helen Keller National Center - Technical Assistance Center (Joan Houghton). (For more information regarding that technical assistance, please see the previous section to this report, **Coordinating Technical Assistance from the Helen Keller National Center - Technical Assistance Center**.)

JC's group home did not accept the fact the JC had both vision and hearing losses. JC's established mode of communication was using conceptually based signs and pencil and paper (providing simple sentences were used). The group home staff never signed to JC and refused to learn sign. The staff believed that JC understood clearly everything that was said to her. They refused technical assistance from HKNC-TAC, the MO 307.11 Project, and from a behavioral consultant even after they agreed to the technical assistance. In addition, JC's classroom staff knew minimal signs.

Outcome. After repeated violent outbursts at school - one resulting in her being handcuffed and removed from the school campus by KC police, JC was expelled from school. Her LEA then secured homebound services from a teacher who could not sign very well. Eventually, this homebound teacher was assaulted. The group home and JC's legal guardian (the State Department of Mental Health) never addressed JC's behaviors. After destroying her bedroom several times and other violent outbursts, JC was sent to a state hospital. The Kansas City Deaf-Blind Task Force attempted to address this issue by bringing about collaboration between the agencies involved, but these repeated attempts were not successful.

4. Youth's name: **LR**
Community: **Montgomery City**
Type of technical assistance: **review of records; and, consultation with teaching staff, parents, and adult service agency staff**
Date of technical assistance: **1 June 1995**

Description of Technical Assistance Activity: The Transition Planning Consultant received a request in May 1995, from the Missouri School for the Deaf for technical assistance on a young woman who was graduating from that institution that June. A transition plan had already been developed by the school and the parents of this youth. The Transition Planning Consultant was asked to meet with the school, the youth's parents, and the director of the adult service agency that would be providing services to the youth upon graduation. During that meeting, the Transition Planning Consultant looked at the transition plan developed and implemented for this youth. The transition plan was well written and unfolding without incident. The Transition Planning Consultant invited the parents and adult service agency to contact him if they experienced any problems in implementing the youth's transition plan or if they felt they needed any additional technical assistance such as additional training for the adult service agency's staff, etc.

In addition, the parents and the director of the adult service agency were informed that the State Deaf-Blind Task Force was planning to create a new local/regional deaf-blind task force that would serve the central region of Missouri including the youth's community. The Transition Planning Consultant promised to connect the adult service agency with the new task force once it was formed.

Outcome: Neither the parents nor the adult service agency have contacted the MO 307.11 Project for additional technical assistance. An organizational meeting of the new local deaf-blind task force in central Missouri was held in October 1995. Notice of this meeting as well as an invitation to participate on the task force was sent to the adult service agency. The agency did not respond to the invitation.

5. Youth's name: **BY**
Community: **Saint Joseph**
Type of technical assistance: **review of records; consultation with teaching staff, parents, and adult service agency staff; attending IEP meetings; writing**

memos clarifying consumer needs; in-service staff training

Date of technical assistance: **3 October 1994; 18 October 1995; 14 October 1994; 29 October 1994; 6 November 1994; 16 November 1994; 21 November 1994; 29 November 1994; 12 December 1994; 19 December 1994; 30 December 1994; 4 January 1995; 5 January 1995; 7 February 1995; 15 February 1995; 21 February 1995; 15 march 1995; 16 March 1995; 29 March 1995; 21 April 1995; 9 May 1995; and, 11 May 1995**

Description of Technical Assistance Activities: BY is a culturally deaf young woman who had been attending the Missouri School for the Deaf which is a residential facility some 250 miles from her home. BY has always experienced some vision impairment (amblyopia and strabismus) and has been on the MO 307.11 census for a number of years. Suddenly in the fall of 1993, BY began to experience a series of retinal detachments in both eyes. She returned to her home community for medical treatment. Surgery and other medical interventions were not successful and BY lost all remaining vision. The school for the deaf eventually informed BY's mother that they could not meet BY's academic needs. Eventually, the school contacted BY's LEA. For some reason the LEA did not respond to the school for the deaf's notification that BY had returned to her community. Eventually, BY's mother contacted the Helen Keller National Center which, in turn, eventually contacted the MO 307.11 Project's Transition Planning Consultant (TPC). The TPC contacted the LEA and referred to provide technical assistance. The LEA accepted and a meeting was set up with BY, her mother, and representatives of the LEA. A series of meetings coordinated by the TPC were held assessing the situation and re-establishing linkage between the LEA and the school for the deaf. Two IEP meetings were held with the school for the deaf attending. The TPC also attended the IEP meetings representing the MO 307.11 Project. Attempts were made by the LEA to have BY placed back into the Missouri School for the Deaf. When this failed, the LEA attempted placement with the Missouri School for the Blind. This also failed. The TPC suggested that the LEA turn to the State and the Saint Joseph Deaf-Blind Task Forces for assistance. Through collaborative efforts between the various agencies on the State, Saint Joseph, and Greater Kansas City Deaf-Blind Task Forces, an arrangement was made between BY's LEA and the Kansas City Schools' Deaf-Blind Program to provide educational services for BY.

Outcomes: BY completed the 1994-1995 school year in a special one-on-one program developed for her by the Kansas City Schools' Deaf-Blind Program. This program focused heavily on providing BY with specialized skills such as Braille, Orientation and Mobility, Activities of Daily Living, English, etc. During the summer, again through collaborative effort on the Kansas City Deaf-Blind Task Force, the Missouri 307.11 Project, and BY's LEA, BY participated in a special summer program at an agency providing services to youth with vision impairments in Kansas City. At the beginning of this current school year, BY's program moved from the KC Schools' Deaf-Blind Program site to a KC high school with a large population of hearing impaired students. She continues to receive training in specialized skills such as Braille and Orientation & Mobility as well as participating in a regular academic program with other hearing and hearing impaired students. In addition, a Personal Futures Plan is currently being developed and implemented by/for her. BY is currently receiving counseling to address her feelings about her vision loss. The 307.11 Project's Transition Planning Consultant continues to provide technical assistance on an as needed basis.

6. Youth's name: **FP**
Community: **Jefferson City and Fulton**
Type of technical assistance: **review of records; consultation with teaching staff, parents, and adult service agency staff**
Date of technical assistance: **1 June 1995**

Description of Technical Assistance Activity: The Missouri School for the Blind contacted the MO 307.11 Project's Transition Planning Consultant (TPC) to provide technical assistance for a transition age youth, FP, who had recently experienced a reduction in visual functioning that was affecting her ability to function at the school. The TPC reviewed FP's medical and other academic records and met with FP's school staff and mother to develop an Action Plan. The Action Plan called for securing a functional vision assessment at the Missouri School for the Deaf in the Fall of 1995' and FP's mother participating in a new local/regional deaf-blind task force to be formed that will serve the Fulton and Jefferson City areas of Missouri. Everyone planned to meet again in September or October 1995 to look at next steps.

Outcomes: A new deaf-blind task force has been formed that serves the central region of the state of Missouri including Fulton and Jefferson City. FP's mother is a permanent member of the task force as well as the Missouri School for the Deaf. The task force has chosen FP as one of its first case studies to use in the process of identifying issues (not limited to only transition issues) encountered when providing services to deaf-blind consumers and their families. This process has just started. In addition, the Transition Planning Consultant has been asked by FP's mother to facilitate the development and implementation of a Personal Futures Plan for FP. The first meeting has been set for January 1996. A functional vision assessment has been scheduled for FP at the Missouri School for the Deaf for early November 1995.

Ushers Screening Conference

Description of Activity:

In the Spring of 1995, the MO 307.11 Coordinator and Transition Planning Consultant discussed the need for developing a statewide screening for Ushers Syndrome. The MO 307.11 Staff began to identify key stakeholders in such an endeavor. Shortly thereafter, the MO 307.11 Project was contacted by the North Central and North East Regional TRACES Coordinators asking if the MO 307.11 Project would be interested in participating in a two day conference to be held the following September (1995) in Pittsburgh, PA, and sponsored by TRACES. The MO 307.11 Project quickly accepted this timely offer. The Transition Planning Consultant completed the necessary paperwork and participated in a conference call with MO 307.11 Project staff from other states, the two TRACES Regional Coordinators, and Dr Sandra Davenport.

Three individuals from Missouri - one representative each from: the MO Department of Health, the MO Rehabilitation Services for the Blind, and the MO 307.11 Project (Transition Planning Consultant) - attended the conference. The two day working conference focused on providing the attendants with information regarding Ushers Syndrome and how to establishing a screening program for this condition.

Outcome:

The attendants from MO developed an Action Plan that calls for the identification of key stakeholders in the state and the creation of a steering committee if there is sufficient interest. Since the conference occurred only weeks before the end of the grant year, there were no other activities to report.

APPENDICES

Component IV
Transition Planning Consultation Services

Appendix A

Workshop Evalutation Summaries: 28 October 1994; 25 - 27 January 1995; 22 May 1995; 11 July 1995; 10 August 1995; 11 September 1995; and, 10 - 11 May 1995

Appendix B

Product Development: *The Future is Around the Corner!*; Training Materials: *Introduction to Deaf-Blindness Workshop*; and, Training Materials: *Developing Communication for Children and Adults with Deaf-Blindness, Module #1*

Appendix A

Workshop Evalutation Summaries:
28 October 1994;
25 - 27 January 1995;
22 May 1995;
11 July 1995;
10 August 1995;
11 September 1995; and,
10 - 11 May 1995

ST. LOUIS ARC
TRAINING EVALUATION
SUMMARY SHEET

Topic: DEAF/BLINDNESS WORKSHOP Date: 10/28/94

Presenter(s): O'BRIEN & RHODES

Number in Attendance: 16

QUESTION #	RATING					
	1	2	3	4	YES	NO
1			2	14	--	--
2				16	--	--
3				16	--	--
4			1	15	--	--
5			1	15	--	--
6			1	15	--	--
7	--	--	--	--	16	
8	--	--	--	--	16	
9	--	--	--	--	14	2
10				16	--	--

Comments: ① I would like more information on this subject more often!; ② I really enjoyed the presentation Thank you.; ③ Good presentation!; ④ Thank you. Enjoyed and learned

Please see following attached sheet for interpretation of rating #s and questions.

BEST COPY AVAILABLE

TRAINING EVALUATION FORM

Topic: ______________________________ Date: ______________

Presenter(s): ____

Circle the number to evaluate the following:

	Unsatisfactory			Excellent
1. **INTRODUCTION** •Defined objectives •Outlined main points	1	2	3	4
2. **KNOWLEDGE** •Knowledge of subject •Used known terminology •Used examples to illustrate points	1	2	3	4
3. **TEACHING QUALITIES** •Appearance, voice •Well organized •Effective use of time	1	2	3	4
4. **DELIVERY** •Composure, eye contact •Gestures, enthusiasm •Use of non-words (um, er, ya know)	1	2	3	4
5. **TEACHING AIDS (If Applicable)** •In proper sequence •Equipment working properly	1	2	3	4
6. **CONCLUSION** •Main points recapped •Provided opportunity for questions •Objective(s) accomplished	1	2	3	4
7. The topic was relevant and valuable?	Yes			No
8. The information gained from this topic will assist me in performing my job?	Yes			No
9. Do you feel a need for additional information about the topic?	Yes			No
10. **OVERALL** I would rank this presentation	1	2	3	4

COMMENTS:

St. Louis Association for Retarded Citizens

Approved 06/94

ST. LOUIS ARC
TRAINING EVALUATION
SUMMARY SHEET

Topic: Deaf/Blind Workshop Date: 1/25,26,27/95

Presenter(s): LARRY RHODES + WAYNE ELROD

Number in Attendance: 10

	RATING					
QUESTION #	1	2	3	4	YES	NO
1		1	4	5	--	--
2			1	9	--	--
3			7	3	--	--
4			3	7	--	--
5		1	6	3	--	--
6			4	6	--	--
7	--	--	--	--	10	
8	--	--	--	--	9	
9	--	--	--	--	4	3
10			4	5	--	--

Comments: ① FIRST DAY WAS SLOW. LAST TWO DAYS WERE MUCH BETTER. LEARNED ALOT FROM THE HANS ON ACTIVITIES. ② CATHI O'BRIEN WOULD HAVE BEEN A GOOD ADDITION TO PRESENTING TEAM - SHE PROVIDES A GOOD PERSPECTIVE ON DEAF CULTURE. ③ GREAT TRAINING - ④ VERY WELL PRESENTED - WAS MENTALLY DRAINING - BUT VERY INTERESTING.

Please see attached/following sheet for interpretation of questions: Rating #'s

BEST COPY AVAILABLE

TRAINING EVALUATION FORM

Topic: ____________________ Date: __________

Presenter(s): ____________________

Circle the number to evaluate the following:

	Unsatisfactory			Excellent
1. **INTRODUCTION** •Defined objectives •Outlined main points	1	2	3	4
2. **KNOWLEDGE** •Knowledge of subject •Used known terminology •Used examples to illustrate points	1	2	3	4
3. **TEACHING QUALITIES** •Appearance, voice •Well organized •Effective use of time	1	2	3	4
4. **DELIVERY** •Composure, eye contact •Gestures, enthusiasm •Use of non-words (um, er, ya know)	1	2	3	4
5. **TEACHING AIDS (If Applicable)** •In proper sequence •Equipment working properly	1	2	3	4
6. **CONCLUSION** •Main points recapped •Provided opportunity for questions •Objective(s) accomplished	1	2	3	4
7. The topic was relevant and valuable?	Yes			No
8. The information gained from this topic will assist me in performing my job?	Yes			No
9. Do you feel a need for additional information about the topic?	Yes			No
10. **OVERALL** I would rank this presentation	1	2	3	4

COMMENTS:

St. Louis Association for Retarded Citizens

Approved 06/94

MISSOURI DEAF-BLIND PROJECT
Training/Workshop Attendance Sheet

Session Title: **Introduction to Deaf-Blindness**

Presenters: **Cathi O'Brien - Bureau of Deaf Services; Larry Rhodes - Missouri 307.11 Project**

Date: **22 May 1995** Location: **South County Habilitation Center**

Participant's Name	Participant's Agency	Name(s) of Deaf-Blind Consumer(s)
Angela Hancock	South County Hab Center	Marcy Grindrod
Denise Bowe	South County Hab Center	
Mary Carlin	South County Hab Center	Marcy Grindrod
Melissa Ryan	South County Hab Center	
Valerie Waites	South County Hab Center	
Marty Williams	South County Hab Center	
Nina Coleman	South County Hab Center	Marcy Grindrod
Kay Auping	South County Hab Center	Marcy Grindrod
Verlillian Foster	South County Hab Center	
Jude Love	South County Hab Center	Marcy Grindrod
Robyn Neath	South County Hab Center	
Mary Smith	South County Hab Center	Marcy Grindrod
Joyce Coffee	South County Hab Center	
Lori Taborek	South County Hab Center	
Laura Sides	Midtown Habilitation Center	
Darlene Smith	Midtown Habilitation Center	

Training/Workshop Attendance Sheet:
Introduction to Deaf-Blindness
22 May 1995
Page 2

Participant's Name	Participant's Agency	Name(s) of Deaf-Blind Consumer(s)
Sharron Watson	Midtown Habilitation Center	Edwina Norris
Lucretia Wilkins	St. Charles Habilitation Center	Sam Gunter
Diana Gibbons	St. Charles Habilition Center	Dennise Cole
Rhonda Wise	Northwest Habilitation Center	Jacki Johnson
Sharon Farrell	Willow's Way	Doris Chott Janice Owens
Dawn Wright	Willow's Way	Doris Chott Janice Owens
Katrina Darnell	Willow's Way	Doris Chott Janice Owens
Mary Stowers	Gateway State School	
Christy Falken	Gateway State School	
Glynn Austin	Gateway State School	

Summary:

Total number of participants: **26**
Total number of agencies: **6**
Total number of consumers and families impacted: **5**
- Doris Chott: 3 staff participated
- Janice Owens: 3 staff participated
- Marcy Grindrod: 6 staff participated
- Edwina Norris: 1 staff participated
- Sam Gunter: 1 staff participated

MISSOURI DEAF-BLIND PROJECT

Summary of Workshop/Training Evaluations

Session Title: **Introduction to Deaf-Blindness**
Presenter: **Cathi O'Brien - Bureau of Deaf Services; Larry Rhodes - MO 307.11 Project**
Date: **22 May 1995**
Location: **South County Habilitation Center**

Number of respondents: **23**
Identified positions/titles of respondents:

Position/title not provided by participants:	6
DA:	5
Habilitation Specialist:	2
Teacher of MH:	1
Classroom Teacher:	1
Speech Therapist:	1
Clerk Typist:	1
Beauty Shop Supervisor:	1
Developmental Assistant:	1
QMRP:	1
Quality Assurance Specialist:	1
SLP:	1
Classroom Supervisor:	1

1. **The content of this session was consistent with the title/description found in the workshop/training announcement.**

Rating	Number of Respondents	Percentage of Respondents
Strongly Agree	18	82%
Agree	4	18%
Neutral		
Disagree		
Strongly Disagree		

NOTE: One respondent did not answer this question.

2. **The level of difficulty was appropriate.**

Rating	Number of Respondents	Percentage of Respondents
Strongly Agree	14	64%
Agree	6	27%
Neutral	2	9%
Disagree		
Strongly Disagree		

NOTE: One respondent did not answer this question.

3. **This session provided me with new knowledge and/or skills.**

Rating	Number of Respondents	Percentage of Respondents
Strongly Agree	13	57%
Agree	10	43%
Neutral		
Disagree		
Strongly Disagree		

4. The presenter used the allotted time efficiently.

Rating	Number of Respondents	Percentage of Respondents
Strongly Agree	16	70%
Agree	5	21%
Neutral	2	9%
Disagree		
Strongly Disagree		

5. The style of presentation was conducive to learning.

Rating	Number of Respondents	Percentage of Respondents
Strongly Agree	14	61%
Agree	9	39%
Neutral		
Disagree		
Strongly Disagree		

6. The presenter made good use of examples and illustrations.

Rating	Number of Respondents	Percentage of Respondents
Strongly Agree	15	65%
Agree	8	35%
Neutral		
Disagree		
Strongly Disagree		

7. The presenter demonstrated a thorough knowledge of the subject matter.

Rating	Number of Respondents	Percentage of Respondents
Strongly Agree	21	91%
Agree	2	9%
Neutral		
Disagree		
Strongly Disagree		

8. I would enjoy attending another session from this presenter.

Rating	Number of Respondents	Percentage of Respondents
Strongly Agree	17	74%
Agree	5	22%
Neutral	1	4%
Disagree		
Strongly Disagree		

9. Teaching aids (slides, audio/visual tapes, handouts, etc.) were effective.

Rating	Number of Respondents	Percentage of Respondents
Strongly Agree	14	61%
Agree	6	26%
Neutral	3	13%
Disagree		
Strongly Disagree		

10. There was adequate time provided to allow satisfactory coverage of this topic.

Rating	Number of Respondents	Percentage of Respondents
Strongly Agree	13	56%
Agree	8	35%
Neutral	2	9%
Disagree		
Strongly Disagree		

11. Physical facilities (room, lighting, sound, temperature, etc.) were satisfactory.

Rating	Number of Respondents	Percentage of Respondents
Strongly Agree	10	44%
Agree	6	26%
Neutral	6	26%
Disagree		
Strongly Disagree	1	4%

NOTE: Additional comments regarding the physical facilities were:
"Hot" "temp!"

12. This session provided knowledge/skills which I feel will make a difference in my work.

Rating	Number of Respondents	Percentage of Respondents
Strongly Agree	18	78%
Agree	4	18%
Neutral	1	4%
Disagree		
Strongly Disagree		

Other comments regarding this session:

- Very informative in-service

- More application to daily activities would have been helpful

- Descriptions of eye and ear could have been shorter and less technical

- I think Cathi O'Brien is neat.

- But the clients that are at my facility doesn't use sign language or body movement. (sic) - need help

INDIANA DEAF-BLIND SERVICES PROJECT
1995 Summer Institute
July 11, 1995

Participant Satisfaction Evaluation

		N	M
1.	The content of this session was consistent with the title/description found in the workshop/training announcement.	12	4.83
2.	The level of difficulty was appropriate.	12	4.66
3.	This session provided me with new knowledge and/or skills.	12	4.75
4.	The presenter used the allotted time efficiently.	12	4.83
5.	The style of presentation was conducive to learning.	11	4.63
6.	The presenter made good use of examples and illustrations.	12	4.5
7.	The presenter demonstrated a thorough knowledge of the subject matter.	12	4.91
8.	I would enjoy attending another session from this presenter.	12	4.83
9.	Teaching aids were effective.	12	4.58
10.	There was adequate time provided to allow satisfactory coverage of this topic.	12	3.83
11.	Physical facilities were satisfactory.	12	3.25
12.	This session provided knowledge/skills which I feel will make a difference in my work.	12	4.41

I intend to apply this information in the following way(s):

- I gained information that was not offered during my college training. I feel much more able to determine/consider the visual needs of my students! My classroom will benefit from this new knowledge.
- This info will help me when reading eye reports and other information was a nice refresher.
- Assist our clients in aspects of their daily living and to provide effective programming for them.
- I may go to Optometry School.
- Reading eye exams for my client.
- To better understand eye evaluations and plan for intervention.
- The handouts will be beneficial to me.
- I will "interpret" vision reports better now and will assist teachers and parents more effectively.

Other comments regarding this session:

- Excellent resource/reference materials were provided. I think too much info was given in too short of time. I would have preferred to have had more in depth info on the more technical parts rather than trying to cover so many "terms." Overall it was an excellent presentation. Larry certainly understands the field and presents info in a very understandable way. Thanks!!
- There was so much information. I think two days would be helpful. I really enjoyed your presentation and your style. The articles you wrote were wonderful!!
- I would have loved to have more time! I enjoyed the content and the presentation of the content. It was a very enjoyable day. Thank you!
- I would have liked the lecture session to be in the morning and group activities in the afternoon. It's just a personal preference to be able to move around in the afternoon.
- Very informative.
- This session was a wealth of information, at times I felt overwhelmed, but having references I can look at later will definitely be helpful. I enjoyed this session more than I thought I would. Thank you.

- Thank you for providing us with all this information. It was a good presentation. Great handouts.

- The day was interesting and informative. I liked the notes provided so we didn't have to copy from the overhead.

- This was an excellent overview -- it could have easily been a two-day session!

The Structure & Functioning of the Visual System and Reading Eye Reports
July 11, 1995

Pre-posttest Results

Code	Pre	Post	Difference
016	8	10	+ 2
015	9	10	+ 1
003	9	10	+ 1
008	10	10	0
010	8	10	+ 2
012	7	10	+ 3
002	7	9	+ 2
014	8	10	+ 2
013	7	10	+ 3
009	8	10	+ 2
007	8	10	+ 2
006	8	8	0
005	5	10	+ 5
Range	5 - 10	8 -10	0 to +5
Mean	7.84	9.76	+ 1.92

MISSOURI 307.11 PROJECT
Workshop/Training Evaluations Summary

Session Title: **Introduction to Deaf-Blindness Workshop**

Presenter: **Larry Rhodes**

Date: **10 August 1995** Location: **Progressive community Services (Saint Joseph, MO)**

List of participants by job title/position:

Community Outreach Coordinator:	**1**
Assistant Director (Agency):	**1**
Agency Director:	**1**
Community Networker:	**1**
Diagnostic Consultant:	**1**
Community Skills Trainers:	**2**
Parents:	**2**
Resource Teacher:	**1**
Total number of participants:	**10**

List of agencies present:

- **Community Recreation and Re-socialization**
- **Kansas City Schools**
- **Parents**
- **Progressive Community Services**
- **Saint Joseph Public Schools**
- **Unity Homes**

Number of transition age youth directly affected by this training:

Youths' Initials	Number of direct and indirect staff trained
JL	**2 (plus parent)**
JH	**3**
ST	**1**
BY	**2 (plus parent)**

Using the scale given below, participants circled the number to evaluate the following statements/questions on the Workshop/Training Evaluation form.

(1) Strongly Disagree (2) Disagree (3) Neutral (4) Agree (5) Strongly Agree

1. **The content of this session was consistent with the title/description found in the workshop/training announcement.**

Response	Number of responses	Percentage of responses
Strongly Agree	**6**	**60%**
Agree	**4**	**40%**
Neutral		
Disagree		
Strongly Disagree		

Mean response: **4.6**

2. **The level of difficulty was appropriate.**

Response	Number of responses	Percentage of responses
Strongly Agree	**3**	**30%**
Agree	**7**	**70%**
Neutral		
Disagree		
Strongly Disagree		

Mean response: **4.3**

3. **This session provided me with new knowledge and/or skills.**

Response	Number of responses	Percentage of responses
Strongly Agree	**5**	**50%**
Agree	**5**	**50%**
Neutral		
Disagree		
Strongly Disagree		

Mean response: **4.5**

4. **The presenter used the allotted time efficiently.**

Response	Number of responses	Percentage of responses
Strongly Agree	**5**	**50%**
Agree	**5**	**50%**
Neutral		
Disagree		
Strongly Disagree		

Mean response: **4.5**

5. **The style of presentation was conducive to learning.**

Response	Number of responses	Percentage of responses
Strongly Agree	**5**	**50%**
Agree	**5**	**50%**
Neutral		
Disagree		
Strongly Disagree		

Mean response: **4.5**

6. **The presenter made good use of examples and illustrations.**

Response	Number of responses	Percentage of responses
Strongly Agree	**5**	**50%**
Agree	**5**	**50%**
Neutral		
Disagree		
Strongly Disagree		

Mean response: **4.5**

7. **The presenter demonstrated a thorough knowledge of the subject matter.**

Response	Number of responses	Percentage of responses
Strongly Agree	**7**	**70%**
Agree	**3**	**30%**
Neutral		
Disagree		
Strongly Disagree		

Mean response: **4.7**

8. **I would enjoy attending another session from this presenter.**

Response	Number of responses	Percentage of responses
Strongly Agree	**4**	**40%**
Agree	**6**	**60%**
Neutral		
Disagree		
Strongly Disagree		

Mean response: **4.4**

9. **Teaching aids (slides, audio/visual tapes, handouts, etc.) were effective.**

Response	Number of responses	Percentage of responses
Strongly Agree	6	60%
Agree	4	40%
Neutral		
Disagree		
Strongly Disagree		

Mean response: 4.6

10. **There was adequate time provided to allow satisfactory coverage of this topic.**

Response	Number of responses	Percentage of responses
Strongly Agree	3	30%
Agree	7	70%
Neutral		
Disagree		
Strongly Disagree		

Mean response: 4.3

11. **Physical facilities (room, lighting, sound, temperature, etc.) were satisfactory.**

Response	Number of responses	Percentage of responses
Strongly Agree	4	40%
Agree	6	60%
Neutral		
Disagree		
Strongly Disagree		

Mean response: 4.4

12. **This session provided knowledge/skills which I feel will make a difference in my work.**

Response	Number of responses	Percentage of responses
Strongly Agree	**4**	**40%**
Agree	**6**	**60%**
Neutral		
Disagree		
Strongly Disagree		

Mean response: **4.4**

13. **I intend to apply this information in the following way(s):**

- All interactions with persons

- Have been made more aware of how others who are Deaf-Blind tend to look at things etc., from there (sic) stand point of not knowing (no meaning to them)

- With Jeanie and Staff

- General broadening of schemata.
- Increases my empathy with consumers and their caregivers!

- I intend to be more sensitive & to think more of what the consumer(s) are feeling.

- When working with James and his staff will be able to reinforce activities and communicate with James with a better understanding of how he is learning about his surroundings

- Communication with client, tell her what is going on more by objects

- Set up communication programs
- Use delivery for other workshops

Other comments regarding this session:

- Enjoyed the excerises (sic)

- Best training ever attended!

- Enjoyable & very worthwhile, learned a lot.
- All of this helps me so much to help Jeannie, and understand her.

- I thought is was very informative. This is somewhat new to me and it helped me understand what the (sic) Deaf-Blind is about.

- Always need a longer amount of time to cover topic

- This information has helped me see how my daughter feels at times & I am trying to be more patient with her mistakes and my mistakes

file name: eval0810.sum

MISSOURI 307.11 PROJECT
Workshop/Training Evaluations Summary

Session Title: **Developing Communication for Children and Adults with Deaf-Blindness - Module #1**

Presenter: **Larry Rhodes**

Date: **11 September 1995** Location: **Progressive Community Services - St Joseph, MO**

List and number of participants by job title/position:

Parent	**1**
ISL Instructor	**2**
Community Networker	**2**
Total	**5**

List of agencies present/number of staff trained:

Progressive Community Services	**2**
Unity Home, Inc.	**2**

Number of transition age deaf-blind consumers directly affected by this training 2

Using the scale given below, participants circled the number to evaluate the following statements/questions on the Workshop/Training Evaluation form.

(1) Strongly Disagree (2) Disagree (3) Neutral (4) Agree (5) Strongly Agree

1. **The content of this session was consistent with the title/description found in the workshop/training announcement.**

Response	Number of responses	Percentage of responses
Strongly Agree	**3**	**60%**
Agree	**2**	**40%**
Neutral		
Disagree		
Strongly Disagree		

Mean response: **4.6**

2. **The level of difficulty was appropriate.**

Response	Number of responses	Percentage of responses
Strongly Agree	**1**	**20%**
Agree	**3**	**60%**
Neutral	**1**	**20%**
Disagree		
Strongly Disagree		

Mean response: **4.0**

3. **This session provided me with new knowledge and/or skills.**

Response	Number of responses	Percentage of responses
Strongly Agree	**3**	**60%**
Agree		
Neutral	**2**	**40%**
Disagree		
Strongly Disagree		

Mean response: **4.2**

4. **The presenter used the allotted time efficiently.**

Response	Number of responses	Percentage of responses
Strongly Agree	**2**	**40%**
Agree	**3**	**60%**
Neutral		
Disagree		
Strongly Disagree		

Mean response: **4.4**

5. **The style of presentation was conducive to learning.**

Response	Number of responses	Percentage of responses
Strongly Agree	**3**	**60%**
Agree	**2**	**40%**
Neutral		
Disagree		
Strongly Disagree		

Mean response: **4.6**

6. **The presenter made good use of examples and illustrations.**

Response	Number of responses	Percentage of responses
Strongly Agree	**5**	**100%**
Agree		
Neutral		
Disagree		
Strongly Disagree		

Mean response: **5.0**

7. **The presenter demonstrated a thorough knowledge of the subject matter.**

Response	Number of responses	Percentage of responses
Strongly Agree	**5**	**100%**
Agree		
Neutral		
Disagree		
Strongly Disagree		

Mean response: **5.0**

8. **I would enjoy attending another session from this presenter.**

Response	Number of responses	Percentage of responses
Strongly Agree	**3**	**60%**
Agree	**2**	**40%**
Neutral		
Disagree		
Strongly Disagree		

Mean response: **4.6**

9. **Teaching aids (slides, audio/visual tapes, handouts, etc.) were effective.**

Response	Number of responses	Percentage of responses
Strongly Agree	3	60%
Agree	2	40%
Neutral		
Disagree		
Strongly Disagree		

Mean response: **4.6**

10. **There was adequate time provided to allow satisfactory coverage of this topic.**

Response	Number of responses	Percentage of responses
Strongly Agree		
Agree	2	40%
Neutral	3	60%
Disagree		
Strongly Disagree		

Mean response: **3.4**

11. **Physical facilities (room, lighting, sound, temperature, etc.) were satisfactory.**

Response	Number of responses	Percentage of responses
Strongly Agree	2	40%
Agree	3	60%
Neutral		
Disagree		
Strongly Disagree		

Mean response: **4.4**

12. **This session provided knowledge/skills which I feel will make a difference in my work.**

Response	Number of responses	Percentage of responses
Strongly Agree	**2**	**40%**
Agree	**2**	**40%**
Neutral	**1**	**20%**
Disagree		
Strongly Disagree		

Mean response: **4.2**

13. **I intend to apply this information in the following way(s):**

- Better communicate with consumer

- Helping Jeannie and her staff - and me

- Better communication for James

- To do the homework and see how much I learn doing so, and apply that knowledge to teach James to expand communication

- to help Jeannie

Other comments regarding this session:

file name: eval0911.95

MISSOURI DEAF-BLIND PROJECT
Workshop/Training Evaluation

Session Title: **Deaf-Blind Orientation and Mobility**
Presenter: **Joan Houghton**
Dates: **May 10 - 11, 1995**
Location: **Bellefontaine Habilitation Center, St. Louis, Missouri**

Identified positions/titles:

(*NOTE: There were 28 participants on Wednesday, May 11, 1995. Only 24 participants completed and returned the Workshop/Training Evaluation Form.*)

Case Manager:	2
Developmental Assistant II:	2
Habilitation Program Assistant (SLARC):	1
Job Coach Assistant (MSB-MHDB):	1
Orientation and Mobility Specialists (RSB):	4
PA^2:	1
Principal (MSB-MHDB):	1
Program Advisor:	1
Teachers Aide (MSB-MHDB):	1
Position/title not indicated:	10

1. **The content of this session was consistent with the title/description found in the workshop/training announcement.**

Rating	Number of Respondents	Percentage of Respondents
Strongly Agree	13	54%
Agree	10	42%
Neutral		
Disagree	1	4%
Strongly Disagree		

2. **The level of difficulty was appropriate.**

Rating	Number of Respondents	Percentage of Respondents
Strongly Agree	8	33%
Agree	11	46%
Neutral	4	17%
Disagree		
Strongly Disagree	1	4%

3. **This session provided me with new knowledge and/or skills.**

Rating	Number of Respondents	Percentage of Respondents
Strongly Agree	14	59%
Agree	8	33%
Neutral	1	4%
Disagree	1	4%
Strongly Disagree		

4. **The presenter used the allotted time efficiently.**

Rating	Number of Respondents	Percentage of Respondents
Strongly Agree	15	62%
Agree	4	17%
Neutral	3	13%
Disagree	2	8%
Strongly Disagree		

5. **The style of presentation was conducive to learning.**

Rating	Number of Respondents	Percentage of Respondents
Strongly Agree	14	58%
Agree	9	38%
Neutral		
Disagree	1	4%
Strongly Disagree		

6. **The presenter made good use of examples and illustrations.**

Rating	Number of Respondents	Percentage of Respondents
Strongly Agree	15	65%
Agree	6	26%
Neutral	2	9%
Disagree		
Strongly Disagree		

NOTE: One participant did not respond this question.

7. **The presenter demonstrated a thorough knowledge of the subject matter.**

Rating	Number of Respondents	Percentage of Respondents
Strongly Agree	16	70%
Agree	5	22%
Neutral	2	8%
Disagree		
Strongly Disagree		

NOTE: One participant did not respond this question.

8. **I would enjoy attending another session from this presenter.**

Rating	Number of Respondents	Percentage of Respondents
Strongly Agree	14	61%
Agree	6	26%
Neutral	2	9%
Disagree	1	4%
Strongly Disagree		

NOTE: One participant did not respond this question.
NOTE: One participant also added the comment: "More details"

9. **Teaching aids (slides, audio/visual tapes, handouts, etc.) were effective.**

Rating	Number of Respondents	Percentage of Respondents
Strongly Agree	10	44%
Agree	7	30%
Neutral	5	22%
Disagree	1	4%
Strongly Disagree		

NOTE: One participant did not respond this question.

10. **There was adequate time provided to allow satisfactory coverage of this topic.**

Rating	Number of Respondents	Percentage of Respondents
Strongly Agree	9	38%
Agree	9	38%
Neutral	5	21%
Disagree	1	3%
Strongly Disagree		

NOTE: One participant did not respond this question.

11. **Physical facilities (room, lighting, sound, temperature, etc.) were satisfactory.**

Rating	Number of Respondents	Percentage of Respondents
Strongly Agree	1	3%
Agree	6	27%
Neutral	6	27%
Disagree	8	35%
Strongly Disagree	2	8%

NOTE: One participant did not respond this question.
NOTE: One participant also added the following comment here: "Hard to view videos/flip charts due to glare and also see interpreter."

12. **This session provided knowledge/skills which I feel will make a difference in my work.**

Rating	Number of Respondents	Percentage of Respondents
Strongly Agree	11	48%
Agree	8	34%
Neutral	2	9%
Disagree	2	9%
Strongly Disagree		

Other comments regarding this session:

- This was a very informative and fun seminar! Thanks

- Wonderful presenter!!

- Joan was very good, flexible to stimulate discussion & to incorporate various ideas & contributions of participants.

- This was my 1st session and learned alot (sic). Thank you so much. (signed) Barb Hanna DSJC

- Hands on training was excellent. Plenty of time allowed to experience the training after "classroom" work. Presenter was very knowledgeable & explained questions so that everyone could understand them. Presenter was approachable and friendly to all.

- This was a very beneficial workshop. I was very pleased with the session.

- Materials should have been provided ahead of time in a requested medium (Braille). Videos could have been accompanied with descriptions. (RSB respondent)

- Participating in the workshop made me more sensitive to the Blind and Deaf. I take for granted that I have sight and hearing but participating in these projects changed all of that. I didn't have much control or I wasn't in control of myself as I would have liked.

- Liked the positive approach on the different techniques to cover same task

- I really enjoyed this workshop. I can use this at my job and also to help other in a different setting. (sic) I work with other clients through respite care and this training will help me. I can help some of the parents at home with maps of their home.

- Would have liked more time for actual work with the cane.

- Room could be better - lighting, etc.

Note. 1 is high
5 is Low!!!

In Service Training Evaluation

Session Title: Orientation and Mobility for Individuals with Dual Sensory Losses

Presenter: Joan Houghton MSED AER O&M

Date: May 10-11, 1995

Location: St. Louis, Missouri

KEY: **1=Strongly Agree** **2=Agree** **3=Neutral** **4=Disagree** **5=Strongly Disagree**

		N	**Mean**
1.	The content of this session was consistent with the title/description found in the Program.	24	1.50
2.	The level of difficulty was appropriate.	24	1.96
3.	This session provided me with new knowledge and/or skills.	24	1.75
4.	The presenter used the allotted time efficiently.	24	1.67
5.	The style of presentation was conducive to learning.	24	1.50
6.	The presenter made good use of examples and illustrations.	23	1.43
7.	The presenter demonstrated a thorough knowledge of the subject matter.	23	1.33
8.	I would enjoy attending another session from this presenter.	24	1.50
9.	Teaching aids (slides, audio/visual tapes, handouts, etc.) were effective.	24	1.83
10.	There was adequate time provided to allow satisfactory coverage of this topic.	24	1.79
11.	Physical facilities (room, lighting, sound, temperature, etc.) were satisfactory.	23	3.0

12.	This session provided knowledge/skills which I feel will make a difference in my work.	23	1.71

O&M Workshop
St. Louis, Missouri
May 10-11, 1995

+	Kaizen
Materials passed out were used. Hands on activities -- best experience of different things. Handouts good for someone who has no experience.	Different room; glare is my enemy. See more equipment, such as TTY. Need consumers to share experiences. Different ways to mix up groups so not all one agency represented. No car prize. Contact participants for equipment. Tapes open captioned. Available materials in braille and large print. Mix up buildings when doing activities. Lunch included. Map of different restaurants in area. Simulation lunch. Lunch in lieu of cookies and donuts. One interpreter for two days is too much. Need two interpreters.

Appendix B

Product Development:
The Future is Around the Corner!;
Training Materials: *Introduction to Deaf-Blindness Workshop*; and,
Training Materials: *Developing Communication for Children and Adults with Deaf-Blindness, Module #1*

The Future is Around the Corner!

A Parent Handbook for Successful Transition

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and
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INTRODUCTION

What job will Shawn have in the future? Will Jennifer go to college? Where will Mary live? What will Jamal do with his friends? These are questions all parents ask themselves when they look forward to the future of their children. Adult life can seem so far away when your child is still in school, yet time passes quickly and before you know it, children are young adults and adult life is a short time away.

This handbook has been written to help you explore these questions, and more, as they relate to your child and family. By exploring the future, you, your child, educators, adult service providers, and others in your community can identify activities that will provide supports and services after high school.

This handbook is divided into these sections:

1. *Transition Overview* addresses the who, what, where, when, why, and how of transition.
2. *Dream of the Future* helps you think about possible future options for you and your daughter or son.
3. *What Can Be Done Now?* will guide home, school, and community activities that can take place now.
4. The *Appendix* includes forms that will help guide your transition planning with your child.

This handbook is written to describe the transition planning process all people with disabilities and their families can use. It is **not** written for any particular group of people who have specific disabilities. Since each child is unique, the transition planning team must make plans and decisions based on the specific needs of each individual and his or her family. To gain the most from this handbook, you must think about how this process will work for your child.

TRANSITION OVERVIEW

Transition Defined

The word *transition* implies movement and change. We all go through changes throughout our lives that have an impact on our future. For example, when a person graduates from high school, then enters a two-year technical school, that person is making a transition that will have an effect on other aspects of his or her life. When a person switches jobs, that person is making a transition. A person can make many transitions in a lifetime.

Have you ever taken a vacation across the country without a map? This trip, like transition, requires a plan to help you successfully end up where you want to be. The time to develop a transition plan is while your son or daughter is still in middle school or high school. Planning early helps design an educational program that will logically prepare your child for the future. Public education is guaranteed by law for all children, but adult services are not. Planning for the services your daughter or son will need as an adult while he/she is still in school will help eliminate gaps in the services needed. Transition planning is also important to help "catch" young adults who are thinking of dropping out of school before graduation.

The federal law called Individuals with Disabilities Education Act (IDEA) requires schools to include transition planning in a student's Individualized Education Program (IEP) at least by the time the student reaches the age of 16. Transition planning may take place prior to the age of 16 if it is needed by an individual student.

Planning for the transition to adult life has some similarities to and differences from developing the IEP. First it is important to know that in Missouri, transition goals, objectives, and activities should be a part of your child's IEP document if your son or daughter is age 16 or older. Second, just as the educational goals and objectives in your child's IEP are developed by a team, so are the transition goals and objectives which become a part of the IEP. A transition team may have participants similar to your child's IEP team and some new people may be invited to the IEP meeting. For example, it may be appropriate to invite a representative from the Job Training Partnership Act (JTPA) who could help your son or daughter find a summer job so important job experience can be gained. Two other state agencies that may provide transition planning assistance are the Missouri Division of Vocational Rehabilitation (DVR) and Rehabilitation Services for the Blind (RSB). They will work with the team to set transition goals and to discuss options available upon graduation. Finally, planning for the future must involve developing a course of action for all aspects of adult life. It would not do much good to plan for and get a job if your son or daughter has no way to get to work. In this example, planning for transportation is very important to keeping a job. Planning must take place for all the adult roles young people with disabilities will soon play.

The Transition Planning Process

Transition to adult life is a complex process. Following are some questions the IEP team members can discuss as they plan for the future for your son or daughter and a list of people who might participate in your child's IEP meeting.

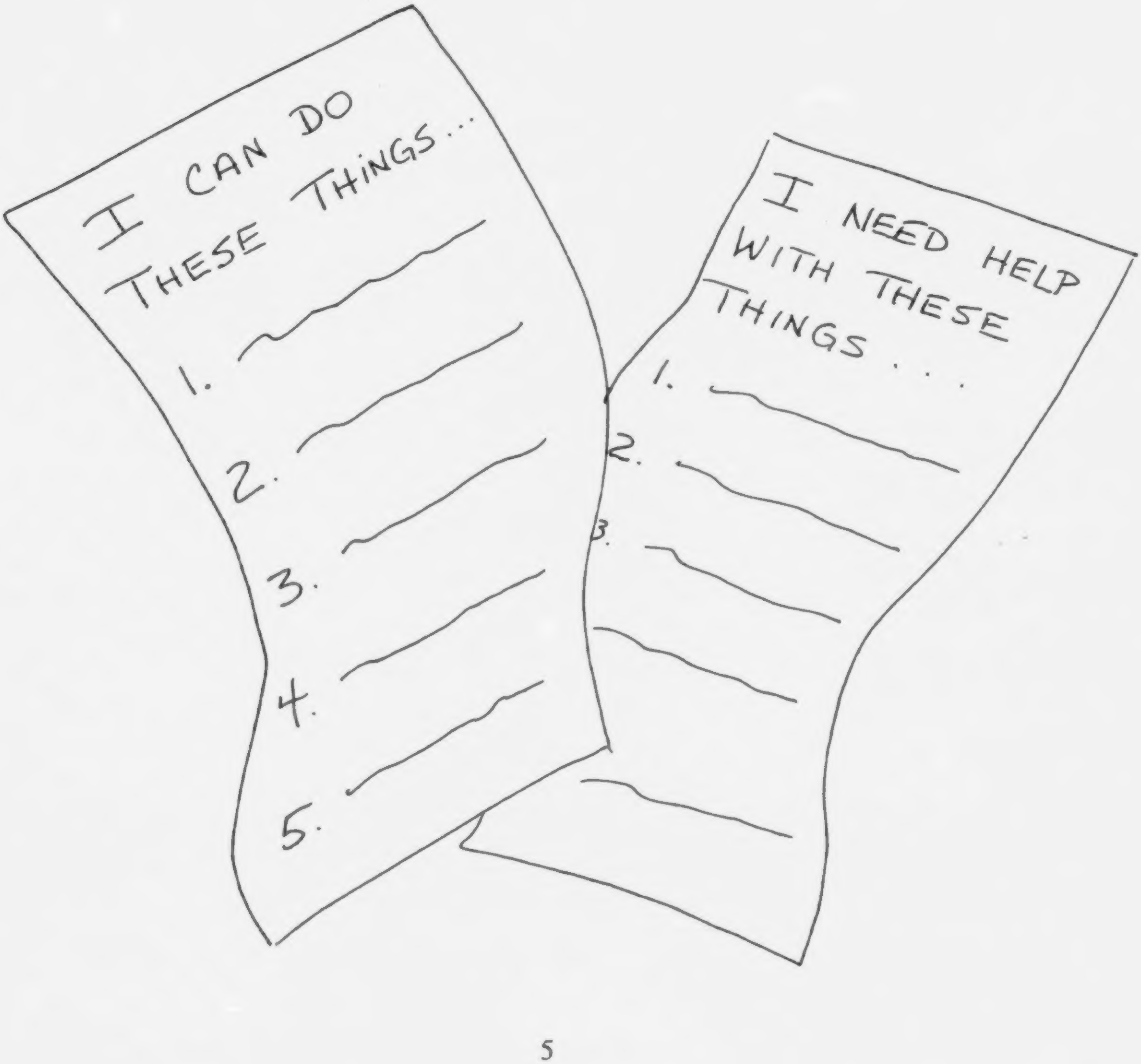
Transition planning is part of the IEP process. Schools are required to address transition during the IEP meeting at least by the time a student is 16 years of age. At the IEP meeting, the team members focus on the future and develop goals and objectives to help your child reach those future goals.

You may have heard the expression: "If you don't know where you're going, any path will take you there." To reach the future, the team must know what path they are taking. To help the team select the right course for your son or daughter, these questions can be discussed. It is suggested that your child be asked to respond to these questions first. After the young adult has had an opportunity to contribute, the other members of the team can build on the student's answers to these questions.

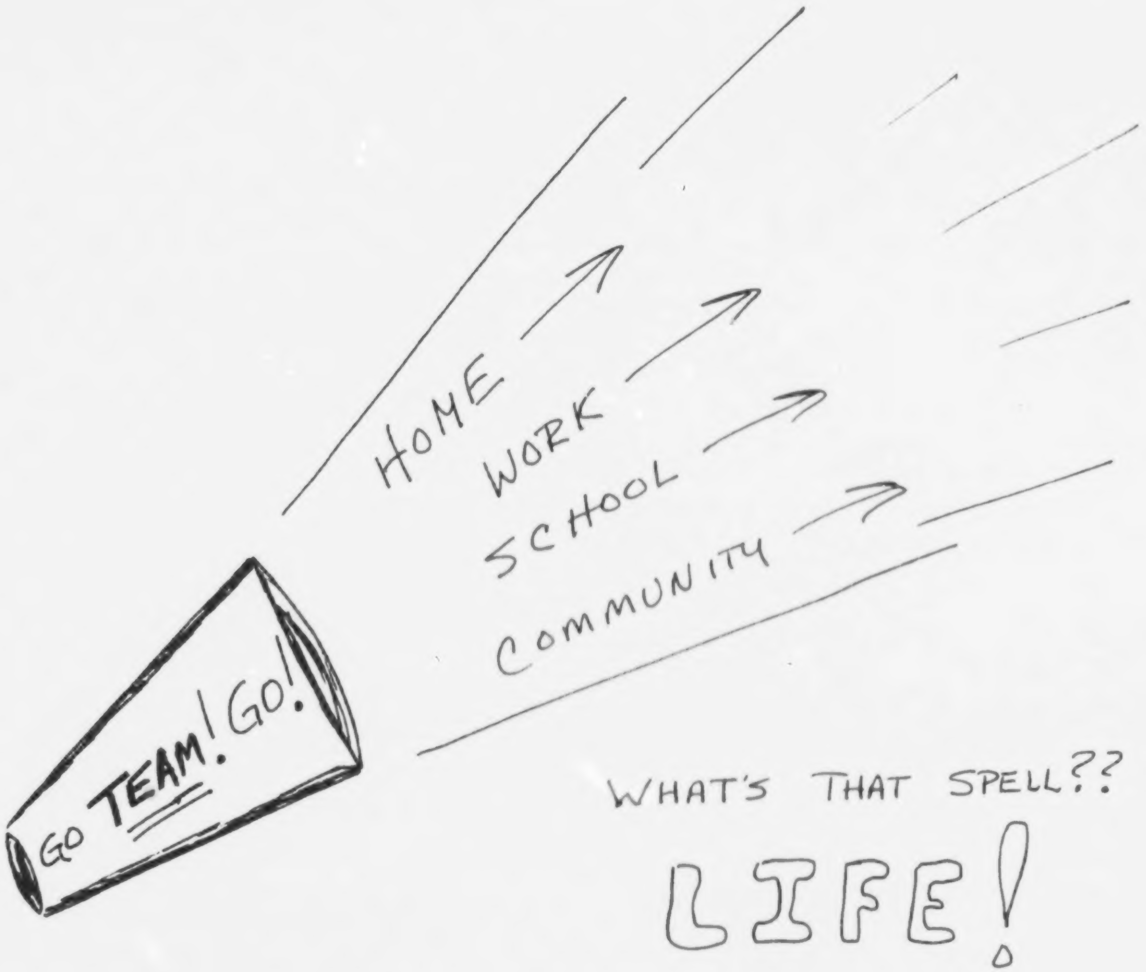
What are your child's dreams after leaving school? The student should be asked to respond to this and other questions about the future, such as: Where would you like to live? What kind of work would you like to do? What activities would you do during free time? How would you get around in the community? What community resources would you use? What support would you need to work, live, and play in the community? The answer to these questions will help the team form transition goals that will be reviewed annually and adjusted when necessary.

SELL CLOTHES?
NURSE?
MARRIED WITH CHILDREN?
AUTO MECHANIC?

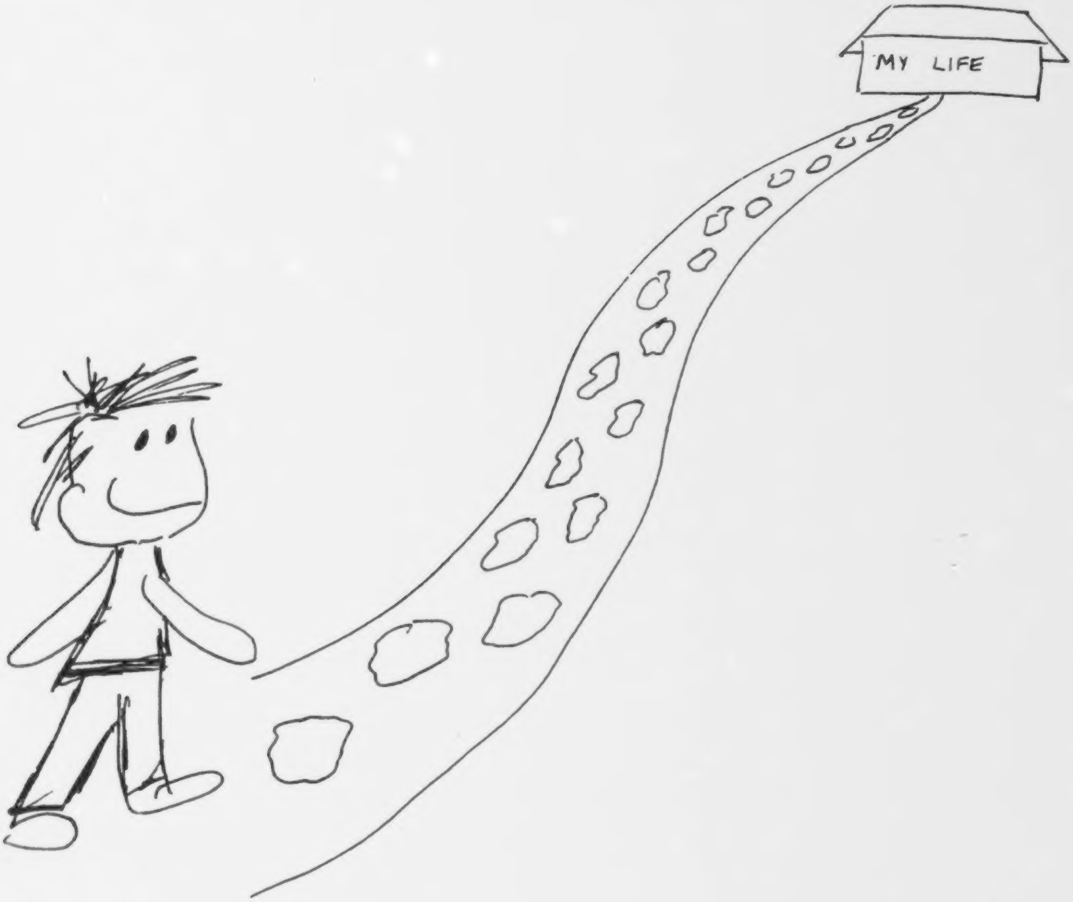
What are you able to do now? Again, your child should describe his or her strengths and interests to the team. The team should not focus only on your child's academic strengths, but should look at all aspects of your child's life. You can help by talking about the chores your child does at home and the activities you do as a family. How is your child involved in the community? Share with the rest of the team the strengths your child shows at those times. Discuss the strengths your child shows when interacting with other kids. Professionals who attend the meeting will also provide information they have gathered. These may be results of formal tests, observations, questionnaires, checklists, and interviews of people who work with your child. Discussing the information that was gathered and the information you have to offer will help form the Present Level of Performance section of the IEP. The Present Level of Performance is a written description of your child's present skills.


I CAN DO THESE THINGS...
1.
2.
3.
4.
5.
I NEED HELP WITH THESE THINGS...
1.
2.
3.

What do you need to achieve your transition goals? The child should talk with the team about his or her learning needs from all areas of life: home, work, school, community, and recreation/leisure. The team should also discuss the support and training needs of your child that go along with learning needs. Some questions to answer are: Does your daughter/son need more opportunities to interact with students who do not have disabilities? Does your child need more learning activities in the community? Does your child need more opportunities to actively explore personal interests? Do you and your child need information about available community services? Answers to these questions will help the team decide how to meet your child's transition needs.



What are you going to do this year? To set annual goals for the IEP, the team should look at the dreams and needs that were shared when answering the questions above. The annual goals must be created by the team specifically for your child. When writing goals, all members of the team can be creative and make the "stepping stones" that lead to long-range transition goals. Again, the team should look at the future recreational, vocational, living, and community dreams of your child.



Who? What? When? Where? How? What Agencies? These questions help the team define the services your child needs. These questions help decide who will take responsibility for seeing that goals are achieved. This turns goals into action! This involves asking questions, such as: What activities does your child need to reach these goals? What is the most relevant learning environment for your child for each activity? What are the teaching approaches to be used? Who is responsible for each goal? When is the progress on each goal reviewed? What agencies are available to assist me in developing my transition goals? When can these agencies become involved?

WHAT?
WHERE?
WHEN?
WHO?
HOW?

The Transition Team

It should be emphasized that many people have responsibility for transition goals. Since transition goals look at all facets of life, it makes sense that you and your child assume responsibility for some goals. For example, your child might be responsible for talking to the school counselor about community colleges that have services for students with disabilities. You might be responsible for contacting adult service agencies who coordinate supported living arrangements. You may want to work on your child's laundry and cooking skills at home, if these are not being addressed in school. Implementation of transition goals should be a shared responsibility.

Transition planning requires that many people be involved. People who should be involved in the transition planning team and their roles are described below.

You. Parents are a critical part of the transition team and the IEP team. To assist with the planning meeting, you may want to think about your desires for your child's future and share your thoughts with school personnel before the meeting takes place (see Parent Input Sheet in the Appendix). Decisions for your child's future need your input, since you will still be a part of that future long after your son or daughter leaves school.

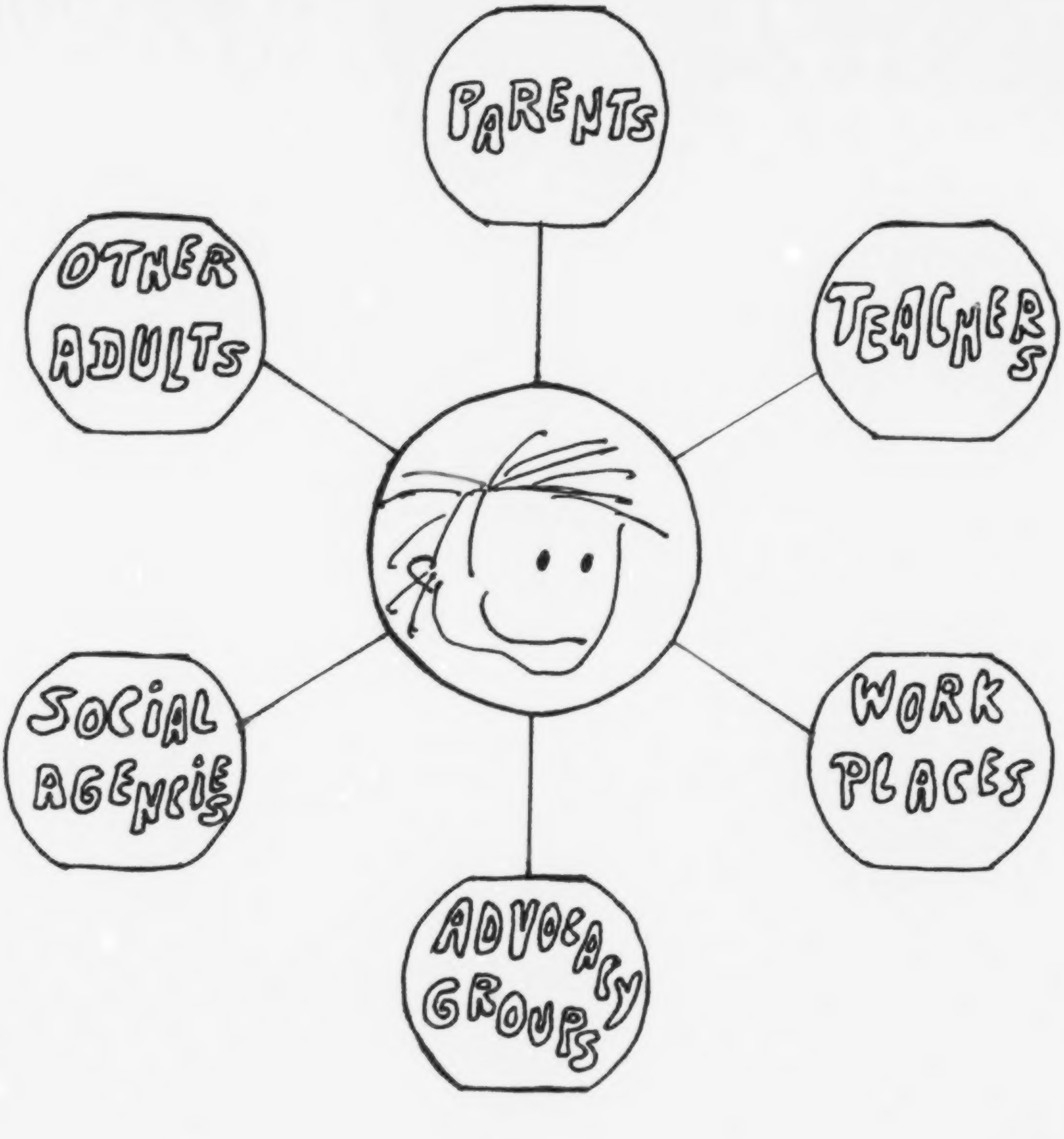
Your daughter/son. IDEA requires that your daughter or son be invited to the IEP meeting if transition goals and objectives are considered. If your child cannot or chooses not to attend the meeting, steps need to be taken to ensure that your child's preferences and interests are considered by the team. Involving your daughter or son teaches your child how to tell others what she/he wants and needs for the future. The program will be more successful with your child's input.

Educators. A special educator, familiar with your child's disability, usually functions as case manager. The case manager's responsibilities include organizing planning meetings, contacting appropriate people and agencies, gathering information, and conducting meetings. The case manager usually runs the meeting and helps the team write transition goals and objectives. This person is actively involved with your child's school program and should be familiar with you and your family. The special educator is also responsible for keeping track of your child's progress, informing you and your child of that progress, and directing you to appropriate agencies. There may also be regular educators, counselors, and therapists working with your child who would be valuable members of the planning team.

Adult service providers. Since adult services are not guaranteed for individuals with disabilities, it is important to involve representatives from other agencies in your son's or daughter's IEP. These agency representatives provide information about services available to your child after he or she leaves school. For example, the Division of Vocational Rehabilitation or Rehabilitation Services for the Blind can be involved with the team in the development of transition plans as early as the student's needs dictate. Often, DVR/RSB will act as consultants up until the time the school is ready for the student to move into off-campus work experience.

At that time, the DVR/RSB counselor will complete an application and determine eligibility for services. They can help your son or daughter sign up for services before he/she leaves school. To locate the adult service agencies in your community, contact the resource centers listed at the end of this manual.

Now that the important members of the planning team have been identified and a process has been described, let's look at the areas of adult life that you, your child and other members of the transition planning team will need to discuss.


PARENTS
TEACHERS
WORK PLACES
ADVOCACY GROUPS
SOCIAL AGENCIES
OTHER ADULTS

DREAMING OF THE FUTURE

For both you and your child, completing high school and moving out into the world can be more than just a little scary. The first step in planning for this transition involves thinking about the future. You, your child, and others who are helping you plan must look at all parts of your child's future. It is important to look at more than work. Where will your child live? How will he/she get to work? How will your child's bills be paid? To help you answer these questions and think about the future, areas of adult life are addressed in this section: employment, living arrangements, activities of daily living, social skills, recreation/leisure, community participation, further education and training, transportation, self advocacy, medical concerns, financial arrangements, legal concerns, and insurance needs. As you read through each topic, think about your child's future and the plans needed for your child to reach his or her dreams.

Employment Options

Finding and keeping a job that enables an adult to maintain a quality life style is part of the American dream and important to most adults. Missouri Division of Vocational Rehabilitation and Rehabilitation Services for the Blind can help you explore the many job possibilities available to your child. To help you think about your child as a future worker, the three general types of work—competitive employment, supported employment, and sheltered employment are described below.

Competitive Employment
Many youth with disabilities leaving high school can get and keep a job without any special support services, just as youth without disabilities do. In a competitive job, workers with disabilities are paid competitive wages and are eligible for the same benefits, such as vacation, insurance, and sick leave as their coworkers without disabilities. Some adults with disabilities may need special accommodations to the work setting to do their work independently. Examples of these accommodations include: a desk raised so a wheelchair will roll under it, a headstick to punch computer keys, or directions provided verbally instead of in writing. Competitive employment is an option for many adults with disabilities.

Supported Employment
Although a large number of adults with disabilities can work independently in the community, others will need ongoing support or supervision to work in the community. This type of employment is called supported employment. Support on the job site helps adults with disabilities, who in the past have been considered unemployable, keep a job. In a supported work situation training and support is given by a person called a job coach or employment training specialist. The job coach is employed by an adult service agency. The job coach has many roles on the job site and, in general, is responsible for training and assisting the worker with disabilities. Another important role of the job coach is to maintain contact with the employer to be sure the employer and coworkers are satisfied with the supported worker's job

performance. The job coach may also help with job related issues such as transportation and purchasing a snack during break time.

Sheltered Workshops

Sheltered workshops are businesses that employ adults with disabilities to do contract work for other businesses in the community. They were created to provide employment for individuals with disabilities and give them a chance to develop skills needed to work in a competitive job. Some workers, however, remain an employee of a sheltered workshop for many years. Many sheltered workshops, such as industries for the blind in many states, were set up to provide long-term employment for its workers. Individuals working in sheltered workshops usually earn salaries below minimum wage, based on their work productivity.

Living Arrangements

Adults with disabilities live in a variety of situations—from 24-hour care facilities to alone in a house or apartment in the community. This range of living arrangements provides adults with disabilities and their families options to meet their needs. Facility living arrangements range from group homes of four or more people with disabilities who live in a typical neighborhood to large habilitation centers where hundreds of adults with disabilities live. Facility living arrangements are staffed to provide training in daily living and personal management skills. In supported living situations, adults with disabilities live and receive support in the household of their choice—an apartment, condominium, or house in a typical neighborhood. Supports are individually designed to meet the unique needs of each person so they may reside in the community. The type and availability of support will vary widely, based on the person's needs, abilities, and the resources that exist or can be developed in his or her community. Examples of supports include: a personal care attendant to get the adult with disabilities up in the morning, dressed and ready for work; a roommate without disabilities who helps manage the checking account and household spending; a neighbor who helps mow the yard; a friend who takes the adult with disabilities to worship with him or her. Finally, many adults with disabilities live independently in the community. These individuals rent or purchase a home and do not require any special support or accommodations.

Personal Management

Closely connected with where your child will live as an adult is performing tasks to care for him/herself. Personal needs such as dressing, toileting, and personal hygiene are important considerations when thinking about the amount of support your daughter or son will need to live independently. The more your child is able to manage household chores such as cooking, cleaning, making purchases, and paying bills, the less support she/he will need from others.

A partial list of some of the daily living skills adults are responsible for include: meal planning, purchasing food and other items, food preparation, eating, housekeeping, telephone use, clothing selection, home maintenance, laundry, health and safety, dressing, personal hygiene, and time and money management.

Socialization/Friends

Getting along with co-workers on the job, sharing an apartment with a friend or spouse, attending any social activity, and responding to feedback from an employer all require good social skills. Social skills are those communication skills used in daily living with friends, family members and coworkers. Good social skills are critical for a happy and productive adult life. Adults who do not have good social skills face many barriers. Not having many friends and not being able to secure and hold any type of job may result in segregation and isolation. Appropriate social skills can lead to improved interactions with others and can help form friendships. Learning to establish and maintain relationships with others is helpful in all aspects of adult life. Social skills all adults need include: getting along with others, resolving arguments with others, getting along with authorities, performing routine chores without being reminded, making friends, working as part of a team, expressing anger in an appropriate way, apologizing, accepting and giving compliments, working without arguing, and having good manners.

Recreation/Leisure

Constructive use of free time is just as important for adults as it is for children. Actively participating in sports, making crafts, or being involved in other leisure activities is important for building friendships and having a quality adult life. Adults with disabilities can learn about and participate in community parks and recreation programs, community centers, YMCAs, YWCAs, church groups, and social organizations. Building and maintaining friendships also increases the likelihood that adults with disabilities will have people to "hang out with." Here is a partial list of future leisure activities: baseball, basketball, bowling, ceramics, camping, arts and crafts, football, sewing, listening to or making music, soccer, knitting, dramatics, bicycle riding, woodworking, scouting, horseback riding, traveling, church activities, watching TV, going to movies and plays, swimming, cooking, building models, shopping, board games, painting, card games, crocheting, and dancing.

Community Participation

Community participation relates to activities and services provided in the general public. These include eating in local restaurants, doing laundry at a laundromat, getting the electricity hooked up for the apartment, shopping for groceries, registering to vote, buying stamps at the post office, going to the high school basketball game, attending worship services, and using other resources in the community.

Further Education and Training

Your child may desire to go from high school into further education at a junior college or university, vocational school, adult basic education program or into a rehabilitation facility.

Junior colleges and universities offer a variety of two and four-year programs that result in a degree. Today many colleges and universities have an office to help students with disabilities obtain the services they need on campus. Your child will have to identify him/herself as having a disability and explain the accommodations needed for success in the classroom. Vocational schools can provide classroom and hands on training that will lead directly to a future trade or job. Adult basic education programs teach adult students reading, writing, and math. Vocational schools and adult basic education programs may also have similar services for people with disabilities.

Transportation

When thinking about your child's future, it is very important to think about how your adult child will get around in the community. In some communities, public transportation may be used to get to and from work and the grocery store. Some other possibilities might be: car pooling, walking to work, using transportation services provided for people with disabilities or learning to drive a car. Transportation considerations are important so work and community opportunities are not lost because there is no way to get there!

Self-Advocacy

Most adults like to have control over their own lives. Adults with disabilities also need to have this control and be able to stand up for themselves. This means being able to describe personal strengths and weaknesses and tell others what accommodations are needed at work and at home. It is also important to know the rights that are guaranteed people with disabilities under the Americans with Disabilities Act of 1990 (P.L. 101-336). This law prohibits discrimination at work and in community businesses. Understanding the law and expressing personal capabilities, limitations and needs are necessary to confront the challenges of adulthood.

Medical

Most adults have medical needs at some point in their lives and some have continuous medical concerns. Adults with disabilities need to learn to take over-the-counter and prescription medication and to go to the pharmacy when the medicine supply is low. Some adults need therapy services and must arrange for a therapy provider and funding for those services. Some adults with disabilities need a personal care attendant to help them live independently. Medical needs must be met to ensure adults with disabilities maintain a healthy, independent life style.

Financial

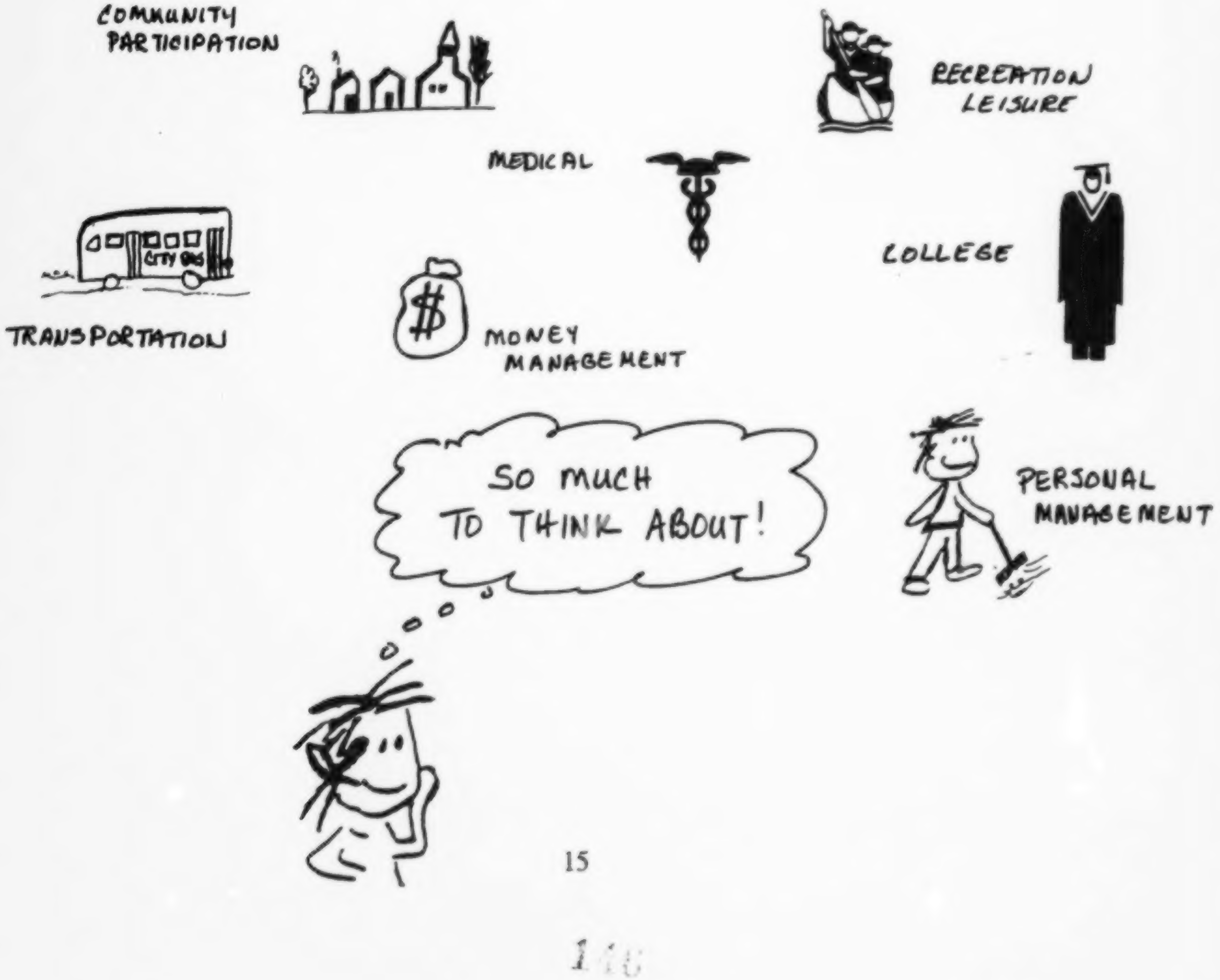
A fact of life is that all adults have to pay bills! Adults with disabilities may need assistance from a public agency, or they may live on their earned income. Financial assistance may be available through Social Security, the Division of Family Services, Employment Security, Vocational Rehabilitation, Rehabilitation Services for the Blind, and the Department of Mental Health. If public assistance is not needed, adults with disabilities must learn to live within their means. Whatever the circumstances of your child and your family, deciding how the bills will be paid is important.

Legal

Guardianship/conservatorship, wills and trusts, and advocacy issues may be important for a secure future for some adults with disabilities. Some adults with disabilities are able to make decisions on their own and do not need another person as a guardian. Some families with a member with a disability will want to insure financial security through wills and trusts. Legal aid, advocacy groups, and attorneys are available to give advice on these important legal issues.

Insurance

Adults with disabilities have a wide range of insurance needs, from Medicaid to various kinds of insurance available to the general public. As an adult, your child may need to know about life, health, dental, workmen's compensation, and automobile insurance. Insurance benefits may be available through work, or private insurance may need to be purchased. Insurance coverage is another fact of life for all adults.


COMMUNITY PARTICIPATION
RECREATION LEISURE
MEDICAL
CITY BUS
TRANSPORTATION
$
MONEY MANAGEMENT
COLLEGE
SO MUCH TO THINK ABOUT!
PERSONAL MANAGEMENT

WHAT CAN BE DONE NOW?

Many skills for adult life can be taught at school and in the home. After the transition planning team has looked toward the future, the skills your child needs to learn before graduation should be identified. This section will address a variety of activities and programs in school and at home that can be implemented before a student graduates from school.

In School

It seems to make sense that the purpose of school is to prepare children for adult life. Elementary and secondary schools can identify specific skills children will need for the future and teach them in the most appropriate way for each individual student. Some students will need to be taught to maintain a real checking account and read the newspaper want ads for a job. It is appropriate that other students be taught the regular school curriculum. If we expect students with and without disabilities to live and work together in the community in the future, we must teach them together now. Schools also need to help all students learn how to develop and maintain meaningful friendships that will last into adulthood. Providing work experience and vocational training programs before graduation is also a responsibility of the school. Like all youth making the transition to adulthood, students with disabilities should be taught to speak up for themselves and become self-advocates. Schools can have a powerful influence on students' abilities to develop their own transition plans. Following is a description of only a few activities and programs schools can offer to help with the transition from school to adult life.

Teaching Future Skills

Once the transition planning team has made plans for the student's future, the curriculum, or what is taught, can be decided. Specific skills the student will need to learn to live, work, and play in the community become the student's program. The IEP team will decide the best methods to teach these skills. For some students with disabilities, most skills should be taught in the same way and in the same setting where the student will use those skills in the future. For example, teaching subtraction can more practically be taught by maintaining a checkbook and making deposits at the local bank. Reading, writing and spelling can be taught by reading newspaper advertisements, making a shopping list, and shopping at the grocery store. For these students, the community becomes their "school."

It is also important for all students to learn their personal strengths and weaknesses and how to communicate those to employers in the future. The student should also learn about his or her disability and the accommodations they will need to successfully live and work in the community. Learning about oneself and communicating personal needs is critical for the future.

Learning Together

Children learn about differences and similarities among a variety of cultures, races, religions, and abilities in school. If the future goal is to live, work and play in the community as adults, children must begin to learn about and with each other in school. Currently schools in Missouri and around the country are providing these learning experiences by teaching increasingly more students with disabilities in regular classrooms. As schools accept all students into their classrooms, plans are needed to ensure that students with disabilities develop friendships and become full members of the school community. One strategy that can be used to facilitate inclusion is the McGill Action Planning System (MAPS). MAPS brings together you, your child, your child's friends and peers, your child's teacher(s), and others, to develop a unique and creative plan to build on the strengths, abilities, and interests of your child to help your child become a part of the school community. MAPS involves a set of questions which this group has equal participation in answering:

1. What is the student's history?
2. What is your dream for the student?
3. What is your nightmare?
4. Who is the student?
5. What are the student's strengths, gifts, and talents?
6. What are the student's needs?
7. What is the student's ideal day?

From these questions, commitments are made to make the ideal day a reality. The MAPS process does not replace your child's Individualized Education Program, but it can become a driving force to assure the most appropriate IEP is put into practice. Although MAPS is typically used for elementary age students, with modifications it can be used for high school students. MAPS brings together people who have a relationship with your child to identify the supports and relationships your child needs to live and learn in the school and community.

Developing Friendships

Starting in the elementary grades, schools can help students with disabilities develop friendships. One way to do this is to form a circle of friends. Friendships are so important to most of us that we cannot imagine a life without others. With friends we laugh, share our troubles, and learn and grow together. Yet many people with disabilities are deprived of mutually satisfying friendships with other people. Sometimes family support, regular schooling, and community living programs are not enough. Everyone needs friends. A formal circle of friends can be convened by school staff or parents by asking acquaintances to volunteer to get more involved in the life of a child with a disability. Peers can find creative ways to help the student with disabilities become more involved in school and neighborhood activities. For example, a phone circle can be formed to call the student in the evening and on weekends. Peers can volunteer to take the student with disabilities to dances, parties, scout meetings, concerts, etc. Peers can also find ways to help the student "fit in", such as suggesting "cool" clothes to wear and teaching the newest dances. Friendships help us rehearse adult roles and a circle of friends can set the stage for the rehearsals to begin.

Providing Vocational Training Experiences

In many high schools a variety of vocational training experiences are available to students with disabilities. Although there may be other options available in your school district, three options, the Cooperative School Work Program, Cooperative Occupational Education (COE) and community-based training are discussed below.

The *Cooperative School Work Program* is a collaboration effort between the local school and the state Division of Vocational Rehabilitation (DVR)and Rehabilitation Services for the Blind. The Cooperative School Work Program is commonly called the co-op program or the work study program. Whatever the name, students with disabilities who can work without the supervision of a job coach or teacher can receive high school credit while working in a community business. In this program, students with disabilities receive valuable work experience during the school day while also earning wages. The high school special education teacher who coordinates the Cooperative School Work Program is called the Vocational Adjustment Coordinator (VAC). The VAC will help you refer your child to the Division of Vocational Rehabilitation counselor to determine if your child is eligible for this program. If your child is eligible for the program, the VAC and the DVR counselor will help your child find a job. After a job is found, the VAC will maintain contact with the employer to monitor the student's progress on the job.

Cooperative Occupational Education (COE) is another program that offers work experience and high school credit to students with disabilities. The COE program helps students prepare for jobs through training at a community job site and in school. COE students usually spend half of the school day in class and the other half day on the job site. To be eligible for the COE program, the student must be enrolled in classes at a vocational technical school (which is part of the public school system). The COE program is offered through Marketing/Distributive Education, Building Trades, Business and Office Technology, or Vocational Agriculture classes.

Community-based vocational training is a third option some schools offer to prepare students for the transition from school to work. Community-based vocational training differs from the Cooperative School Work Program and the COE program in that a school employee usually provides supervision and training to the student while the student is at a community job site. Many schools that offer community based vocational training place the student in several different jobs to give the student a variety of experiences. These varied experiences help determine what type of job the student likes to do and what she/he is good at doing. During the last year of school, efforts should be made to teach the student a job that he or she can keep after high school graduation. If the student will need to have a job coach after graduation, connections with an adult service agency that provides supported employment services must be made early. Remember that adult services, such as supported employment, are not automatically provided, and a gap between high school and supported work may occur if early planning does not take place.

Teaching Self-Advocacy

One of the most important skills schools can teach students with disabilities is to stand up for themselves. Most people like to take charge of their lives. People with disabilities do too! Teachers and counselors may hinder self-advocacy when they accept the role of "expert" about the student's needs and the school program. To gain control over their futures, teachers must teach students with disabilities the skills needed to make informed decisions about their lives. To be successful in the world of work, in the community and in social relationships students with disabilities must have an understanding of and ability to express their capabilities, limitations and needs; know and stand up for their rights while respecting the rights of others; and accept responsibility to contribute their ideas and skills. Students with disabilities must be afforded opportunities to develop and practice these self-advocacy skills before they are confronted with the increased demands and expectations of adulthood.

At Home

Parents also have some responsibility for preparing their child for adult life. Home is the best place to teach many homemaking, money management, mobility, recreation/leisure, and social skills. Parents prepare their children for the future by providing choices and getting the student involved in a variety of activities. Following are a few suggestions to help prepare your child for the future.

Teaching Skills

Parents teach valuable skills that will be helpful in adult life. Homemaking skills such as doing the laundry, washing dishes, or vacuuming can be taught. Giving your child the responsibility to do these tasks will help her/him develop the independence to do these chores in the future. Although it may seem easier to do chores yourself, the time you take to teach your child will be worth it. It is also important that your child does household chores as all the other family members do. This helps your child feel like a contributing member of the family.

Families can also teach money management skills by giving the child an allowance and helping the child make saving and spending decisions. Family members can also teach a child with a disability how to get around in the community. As a younger child, this might mean learning how to walk to school or a friend's house. For a youth capable of learning to drive, the family can help him/her study for the driver's test. Families also can play an important role in involving their child in recreation/leisure activities. By learning to play a variety of games at home, in the neighborhood, or in organized recreation programs, children learn how to manage their free time and how to get along with others—both valuable skills for the future.

Giving Choices

You can help prepare your child to make decisions that adult life demands. One way to begin teaching your child to make decisions is to give your child choices and honor those choices. People make choices hundreds of times a day. Yet many times, adults limit the choices children are allowed to make. Usually this is done with the intention of being helpful and not wanting the child to fail. Sometimes it is difficult to let go and allow your child opportunities to discover things on his or her own. Yet making choices is part of this discovery process. Choices can be small, such as choosing the red shirt or the blue one. Decisions can be more important and difficult to make, such as choosing to live in a group home or in a supervised apartment. Learning to make and live with choices that are made are valuable lessons for adult life. Some of life's most valuable lessons are taught when poor choices are made and another decision has to be considered. Parents need to think about how they can offer many choices throughout the day to help prepare their children for adult life

Getting Involved in Typical Activities

All families want to protect all the family members. It is easy to become overprotective and therefore, limit your child's experiences. Although it may be scary and difficult, it is important to encourage your child to be involved in typical activities in school and the community. It is important to encourage your daughter to be in Brownies or go to the football game and school dance on Friday night. Playing with Barbie like the other second grade girls, wearing "cool" clothes and going to pizza parties are important for making friends and "fitting in." By participating in these activities, kids learn how to get along with others and this helps prepare your child for community living and work in the future. If your son or daughter has developed a network of friends and interest in a variety of activities while in school, it is likely those skills and interests will continue into adult life. Again, it is important to let go enough to help prepare for the future—a place to live in the community, a social network, and a job or further training.

GETTING HELP FROM AGENCIES AND LOCAL RESOURCES

Adult services are not mandated as is school. Therefore, it is important to know the resources that are available to people with disabilities. As your family is going through this change of a member graduating from high school, it may be very helpful to get assistance from state and local agencies and resources. Representatives from agencies and resources in your community will provide valuable input into the requirements and qualifications for their agency. Agency personnel also will provide helpful information about the skills needed to be a happy and successful adult.

When planning for transition it is important to look at the resources available to all citizens of your community. For example, many recreational and social activities are offered by city recreation departments or the local YMCA. Civic groups and organizations provide activities and events for citizens in the community. Adult education classes are available to adults who want to discover a new hobby, improve their work skills, or to learn home improvement techniques. Each community has unique resources which can provide its citizens with new opportunities and experiences.

The following organizations can help you identify agencies and resources available to your child in transition. They can help you complete the resource sheet at the end of this manual and make it specific to your child's transition needs.

INFORM is the Information Network for Missouri's Children with Special Needs. INFORM maintains an up-to-date listing of all agencies, services, and programs within the state of Missouri which serve children and families with special needs. A trained person will answer your call, help you find resources in your area and keep your call confidential.
The services of INFORM are available by calling toll free, **1-800-873-6623.** TT/TTY use may access INFORM through Relay Missouri at 1-800-735-2966.

The Center for Innovations in Special Education serves special educators and others involved with the education of children and youth with disabilities. The Center for Innovations in Special Education can help you locate local agencies that provide services in your community. To access names and addresses of service agencies, call the toll-free number, **1-800-976-CISE.** TT/TTY users can access the Center for Innovations in Special Education through Relay Missouri at 1-800-735-2966.

Missouri School for the Blind provides information about and services for children with blindness and deaf/blindness. Missouri School for the Blind staff are familiar with other agencies that provide services to children with vision impairments/blindness. Contact the Missouri School for the Blind at **1-800-622-5672.** TT/TTY users can access Missouri School for the Blind through Relay Missouri at 1-800-735-2966.

MPACT is the Missouri parent-to-parent information, training, and support center. MPACT serves parents of children with disabilities from three offices:

Springfield: **(407) 882-7434** (Voice or TDD) or **1-800-743-7634.**
St. Louis: **(314) 997-7622** (Voice or TDD) or **1-800-995-3160.**
Kansas City: **(816) 333-6833** (Voice) or **(816) 333-5685** (TDD).

Resource Center on Deafness is an information resource available from the **Missouri School for the Deaf.** The Resource Center on Deafness reaches out of Missouri's deaf and hard-of-hearing children and can be reached at: **(314) 592-2543 (TDD and Voice).**

The Missouri Governor's Committee on Employment of People with Disabilities maintains an information resource center. The Governor's Committee cooperates with many other agencies and is aware of agencies and services available throughout Missouri. For information, contact the following Governor's Committee offices:

Jefferson City: **(314) 751-2600** or **1-800-877-8249** (voice or TTY/TDD).
St Louis: **(314) 832-7443** (voice or TDD).
Kansas City: **(816) 889-3012** (voice) TT/TTY users have access through Relay Missouri at 1-800-735-2966.

Missouri Division of Vocational Rehabilitation (main office)
2401 E. McCarty
Jefferson City, MO 65101-4400
(314) 751-32551 (Voice) or (314) 751-0881.

Rehabilitation Services for the Blind
Division of Family Services
619 E. Capitol Avenue
Jefferson City, MO 65101
(314) 751-4249.

Adult Services Referral and Contact List for Transition Planning

Referral Needs	✓ Need	Contact/Agency Name, Address, Telephone
Supplement Security Income		
Medicaid		
Medicare		
Division of Rehabilitation		
Department of Mental Health		
Division of Mental Retardation		
Independent/Supported Living		
Vocational Training		
Residential Services		
Transportation Services		
Recreation/Leisure		
Respite Services		
Family Support		
Counseling		
Guardianship		
Other		

Source: Committee on Transition (March, 1994). *Resources to help students plan for the future.* Portland, ME: Author

Parent Input for Transition Training

So you will be prepared to develop a working transition plan, please answer the following questions. This information will be valuable for the IEP team when developing a post-school program.

1. Will your child be able to enter the adult world without special support beyond the family?

2. Do you know what services are available for your child once he/she reaches graduation?

3. Do you have short-term and long-term arrangements for financial support of your child?

4. Will your child have insurance?

5. What kind of work do you see your child doing? What does your child want to be?

6. What living arrangements will you expect or like your child to have?

7. Does your child have adequate self-help skills if left unattended?

8. Does your child have favorite leisure activities? If so, what are the activities your child enjoys?

9. What kind of transportation will your child need after graduation?

10. Does your child require special medical attention?

(Adapted from Midwest Regional Resource Center, 1982)

Introduction to Deaf-Blindness Workshop

18 December 1995
Central Missouri Deaf-Blind Task Force

Presented by:
Larry Rhodes - Missouri 301.77 Project

BEST COPY AVAILABLE

Agenda

Introduction to Deaf-Blindness Workshop

18 December 1995
Central Missouri Deaf-Blind Task Force

Agenda

9:00 am - 9:10 am	Introductions
9:10 am - 9:15 am	Purpose of the workshop
9:15 am - 9:30 am	Dynamics of Deaf-Blindness and Etiologies in the Deaf-Blind Population
9:30 am - 9:45 am	The Eye and How It Works (The Eyeball Made Easy)
9:45 am - 10:00 am	What are Visual Acuities and Visual Fields?
10:00 am - 10:15 am	The Five Types of Vision Loss
10:15 am - 10:30 am	Break
10:30 am - 11:00 am	The Five Types of Vision Loss (Con't)
11:00 am - 11:30 am	Activity: "Whatzit?"
11:30 am - 11:45 am	Possible Developmental Delays of a Child with a Severe Vision Impairment
11:45 am - 12:00 am	Set-Up for Activity: Lunch
12:00 am - 12:30 pm	Activity: Lunch

12:30 pm - 12:45 pm	Process Lunch Activity
12:45 pm - 1:00 pm	Break
1:00 pm - 1:15 pm	How We Hear
1:15 pm - 1:30 pm	Types and Degree of Hearing Loss
1:30 pm - 2:00 pm	Activity: Hearing Loss Simulations
2:00 pm - 2:15 pm	How Hearing Loss Affects Communication and Concept Development
2:15 pm - 2:30 pm	Break
2:30 pm - 3:00 pm	Communication Modes
3:00 pm - 3:45 pm	Activity: Non-Verbal Deaf-Blind Communication
3:45 pm - 4:00 pm	Tying It All Together
4:00 pm - 4:15 pm	Wrap-up and Evaluation

Purpose and Rules

Purpose of the Workshop

To provide:

- a basic awareness of vision and hearing losses and how these losses affect an individual's development and functioning in her/his environment;

- a basic awareness of how the combination of deafness and blindness creates a whole new set of dynamics affecting how the Deaf-Blind consumer relates to other individuals and to the environment;

- an opportunity to experience the dynamics of deaf-blindness; and,

- a foundation for future, expanded training in specific topic areas relating to deaf-blindness: Communication, Social Skills, Orientation and Mobility, Independent Living Skills, Recreation, Job Development and Placement, etc...

Rules for the Workshop

1. Participant must plan to stay the entire day.

2. The presenter will *not* use "People First Language" when referring to Deaf-Blindness. The presenter will adhere to the preference of the adult Deaf, Blind, and Deaf-Blind Communities and refer to these individuals as Deaf Individuals/Consumers, Blind Individuals/Consumers, and/or Deaf-Blind Individuals/Consumers.

3. The presenter will start and stop on time.

4. There are no "bad" questions.

5. Relax and enjoy yourself during this workshop.

FACTS AND MYTHS ABOUT DEAF-BLINDNESS

(A short test)

FACTS AND MYTHS ABOUT DEAF-BLINDNESS

Many people hold a number of misconceptions and misunderstandings about the dual sensory impairments described by the label of deaf-blindness. Read each of the following statements. Which ones do you think are facts? Which ones do you think are myths? Circle the one best response for each statement.

1. People who have been assigned the label deaf-blindness are both totally deaf AND totally blind

FACT MYTH

2. As a result of the rubella vaccine developed in 1969, children are seldom labelled as deaf-blind and professionals need not worry about developing the skills to address this low-incidence disability group.

FACT MYTH

3. Usher Syndrome, the combination of congenital deafness and progressive blindness due to Retinitis Pigmentosa, is a leading cause of deaf-blindness among adolescence and young adults.

FACT MYTH

4. There are minimal differences in the characteristics and support needs of individuals born deaf-blind (congenitally deaf-blind) and those of individuals who become deaf-blind later in life (adventitiously deaf-blind).

FACT MYTH

5. Regardless of the age of onset or severity of the dual disabilities, communication and orientation and mobility are common support needs of individuals who have been labeled deaf-blind.

FACT MYTH

6. Typically, individuals who have been labeled deaf-blind are unable to work or live in integrated community settings.

FACT MYTH

(developed by HKNC-TAC)

Dynamics of Deaf-Blindness

and

Etiologies in the Deaf-Blind Population

Dynamics of Deaf-Blindness
and
Etiologies in the Adult Deaf-Blind Population

What is Deaf-Blindness?

"Deaf-Blind" refers to two sensory impairments, visual and hearing, occurring in combination with each other. The combination of these sensory losses causes significant education and rehabilitation problems.

For the purpose of this workshop, we will use the Federal definition of Deaf-Blindness used to identify deaf-blind children:

The Federal Definition of Deaf-Blindness

> The term "Children with deaf-blindness," means children and youth having auditory and visual impairments, through combination of which creates such severe communication and other developmental and learning needs that they cannot be appropriately educated without special education and related services, beyond those that would be provided solely for children with hearing impairments, visual impairments, or severe disabilities, to address their educational needs due to these concurrent disabilities.

- The Federal Register,
October 11, 1991, page 51585

Why do we want to use the Federal definition?

Because it is *functional.*

When we are working with a Deaf-Blind adult, we need to ask ourselves:

-Does this individual have enough vision to compensate for her/his lack of hearing?

- Does this individual have enough hearing to compensate for her/his lack of vision?

If the answer is *"NO"* to both of the above, you are working with an individual who is deaf-blind.

The term "Deaf-Blind" does not always mean *totally* blind and *totally* deaf. Most deaf-blind people actually have some residual hearing and/or vision.

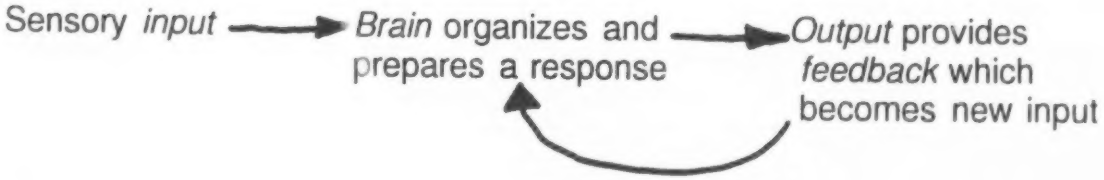
What makes the combination of deafness and blindness so unique?

Vision and Hearing are our two *distance* senses; they bring the world to us. Loss of these two senses deprives us of the two primary senses through which we learn about the environment and the world at large.

Because of these to losses - vision and hearing - the person who is deaf-blind, particularly if deaf-blind since birth, may experience cognitive problems that may resemble those experienced by individuals with developmental disabilities. Behaviors of an individual who has been deaf-blind since birth may resemble those of an individual with autism. This is because the deaf-blind individual's incoming information about the world is distorted.

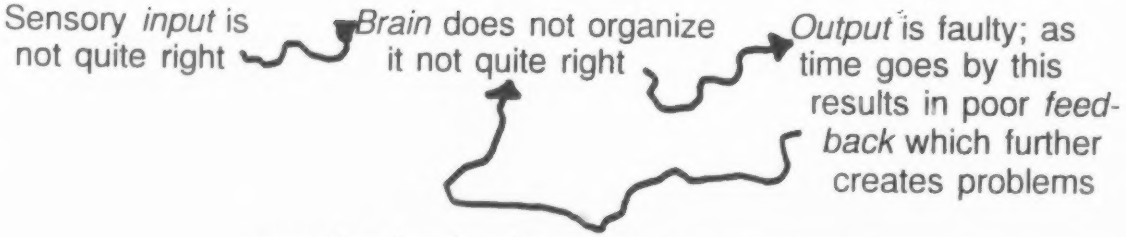
On the next page is a chart that provides a simple way of looking at sensory integration and how a combined vision and hearing loss can creative cognitive delays. The diagram is a modification one developed by Jean Ayers.

NORMAL


Sensory *input*
Brain organizes and prepares a response
Output provides *feedback* which becomes new input

good feedback reinforces good responses

DEAF-BLIND


Sensory *input* is not quite right
Brain does not organize it not quite right
Output is faulty; as time goes by this results in poor *feedback* which further creates problems

poor feedback reinforces poor responses

If, in addition, the person also has developmental disabilities or cerebral palsy, the poor feedback cycle is further reinforced.

Four Categories of Deaf-Blindness

1. Congenitally Deaf, Adventitiously Blind (born Deaf/Hearing Impaired and later lost vision)

   Some causes of vision loss:
   Retinitis Pigmentosa (RP)/Ushers/Other Related
   Macular Degeneration
   Diabetic Retinopathy
   Cataracts
   Retinal Detachment

2. Congenitally Blind, Adventitiously Deaf (born Blind/Visually Impaired and later lost hearing)

   Some causes of hearing loss:
   Unknown
   High Fevers
   Diabetes
   Kidney Failure
   Pollution/Toxins
   Trauma
   Genetic Factors
   Presbycusis

3. Congenitally Deaf-Blind (born Deaf-Blind)

   Some Causes of Congenital Deaf-Blindness:
   Prenatal Disfunction:
      AIDS
      Rubella
      Toxoplasmosis
   Syndromes
      Down's
      Trisomy 13
   Multiple Congenital Anomalies
      CHARGE Association
      Fetal Alcohol Syndrome
      Maternal Drug Abuse

Prematurity
Pre- and Post Natal Trauma
Meningitis
Encephalitis

4. Adventitiously Deaf-Blind (born with normal vision and hearing and later lost both)

Some causes of deaf-blindness:
Illness
Trauma
Genetic Factors
Age related vision and hearing losses

How Can I Begin to Understand the Dynamics of Deaf-Blindness?

To help you better understand the dynamics of deaf-blindness, let's first explore vision and hearing losses separately, examining how each alone affects an individual's development and relationship with the world.

Not only will you learn about the effects of vision and hearing loss - individually and together - "academically" through lecture, but also experiencially through planned activities.

At the end of this workshop, we'll tie together all of your experiences by taking a closer look at deaf-blindness.

The Eye and How It Works
(The Eyeball Made Easy)

INSITE RESOURCES FOR FAMILY CENTERED INTERVENTION FOR INFANTS, TODDLERS, AND PRESCHOOLERS WHO ARE VISUALLY IMPAIRED

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TOPIC 1: ANATOMY OF THE VISUAL SYSTEM

GOAL

Parents and other caregivers will know the parts of the visual system and be able to explain what is wrong with the child's visual system.

MATERIALS

- Diagram V-1, "The External Structures Surrounding the Eye"
- Diagram V-2, "The Human Eye"
- Diagram V-3, "The Natural Blind Spot"
- Diagram V-4, "Optic Nerve Pathway In the Brain"
- An eye model or colored eye anatomy chart (A model and chart can be purchased from the American Optometric Association, 243 North Lindberg Blvd, St. Luois, MO 63141. A simple eye anatomy illustration entitled "How We See" is available free from the National Society for the Prevention of Blindness, 79 Madison Ave, New York, NY 10016)
- A penlight
- Mirror

INSTRUCTIONS TO EARLY CHILDHOOD SPECIALIST

For many parents, it is advisable to shorten this discussion to cover only the key anatomical parts of the visual system. Another option is to share the information over two or more visits. Specific names of some ocular disorders will be listed in brackets as a note about what disorders relate to damage or abnormalities in the part of the visual system being discussed. When talking about the parts of the visual system which relate to the child's ocular disorder, take time to cover what has been damaged in that part of the child's visual system.

This means that the early childhood specialist will need to know what the child's ocular disorder is ahead of time and should have done some reading on it or have discussed it with a vision consultant. Ask the parents (or caregivers what information they have obtained about the child's ocular disorder from the child's eye doctor(s). This, and the following topic, should help them make sense of the information if they do not, as of yet, understand it. Stop occasionally to see if they have questions or comments. A reference guide to ocular disorders in young children is found in Appendix C on page 638. Look up the specific ocular disorder in that guide. Remember that information on ocular disorders and treatment is constantly changing with medical advances, so consult the child's eye doctor(s) for the most up-to-date information.

SAMPLE DISCUSSION

Today, we will look at how the human visual system is put together, some of the things that may be damaged, and what, specifically, has happened to your child's visual system. We use the words "visual system" because vision and seeing involves more than just the eyes; they also involve special nerves called the optic nerves that connect the eye to the brain as well as a certain part of the brain called the visual cortex that actually does the "seeing". All of this together is called the visual system. When something happens to any of these parts, vision loss can occur.

Let's start at the very beginning. The majority of the eye's development takes place during the first three months of pregnancy, the embryonic period. The eyeballs appear as two little buds of brain material extending from the rest of the brain and connected to it by what will later become the optic nerves. Therefore, the eyes are really an extension of the brain exposed to the outside world!

It is during this first three months of pregnancy that things can differ from what is expected. For example, viruses (e.g., rubella, cytomegalovirus or CMV), infections and certain drugs taken by the mother can alter how the eye is formed If the genes that control the development of the eyes are abnormal, this is when malformations take place. Often, these are things and events over which the mother has no control and which the best eye doctor in the world could not have predicted or prevented. They just happen. [If the child's eye report indicates an etiology such as albinism, retinoblastoma, Down or CHARGE syndrome; or if the child's mother contracted a virus or other infection during her pregnancy that resulted in vision problems such a cataracts caused by rubella; or if the child has an ocular deformity such as anophthalmia or coloboma, take time to discuss it with the parents if they are comfortable in doing so.]

Slowly, the structures of the visual system--the eyeballs, the optic nerves, and the visual cortex--develop and become refined. A full term baby with no visual problems is born with an almost completely developed visual system. The newborn's visual acuity (his ability to see things sharply or clearly) is poor, but the baby's acuity approximates 20/20 by the age of 12 months due to maturation of the nervous system. Because a young baby sees objects much better when the objects are within one to two feet from his eyes, human faces attract a good deal of his visual attention. This attraction is reinforced because a baby is generally held cradied in someone's arms when he is being nursed or feed. This also helps in the bonding process between the infant and his parents. Bright, colorful objects and toys within arm's reach also attract his attention.

During the first few months of life, the baby's eyes are not always in alignment when he is looking at something or following it with his eyes. One eye may turn in or out. However, by the time the baby is 6 months old, both eyes work well together as a team.

Just as there are things that can cause damage to the visual system when it is developing during the first three months of pregnancy, a number of things can cause damage to the visual system during delivery and in the weeks and months after a baby is born. They can include a difficult birth (e.g., the baby does not get enough oxygen), premature birth, infection and disease, prolonged hydrocephalus and accidents resulting in head injuries. From birth until about 18 - 24 months, a baby's brain is still considered to be immature because the nerve pathways in the brain are still forming. This makes the baby more susceptible to brain injury. [If the child's eye report indicates an etiology that occurred during birth or the months thereafter, take time to discuss it with the parents.]

Let's take a closer look now at this visual system, starting with the eyeball and working our way back to the visual cortex. [To aid in describing the information contained in the next three paragraphs, point out the structures being discussed using Diagram V-1, "The External Structures Surrounding the Eye".]

The eyeball lies within an indentation of the skull called the orbit. The orbit is made up of bones in the skull. The upper bone also forms the eyebrow and the lower bones form the cheekbone. These bones, along with soft, cushiony tissue around the eye, help protect it from direct impact. The front of the eye is also protected by the eyelids and lashes. Glands found in the lids and above the eye (not indicated in the diagram), make the tears that bathe the front of the eye, lubricate it and help to prevent infections. Every time you blink, this happens.

Try to keep your eyes open, and do not blink. What do you feel? Burning or stinging? This is because the front of your eye, or cornea, is drying out.

Each eyeball has six muscles connected to it on the outside called extraocular muscles. These muscles hold the eyeballs in place as well as move the eyeballs. Two or more of these muscles, working together, move each eyeball up, down, diagonally and to the side. These eye movements are important for visually searching for things, looking at these things, and visually following these things as they move. The muscles are hooked up to nerves that are controlled by the front part of the brain, the frontal lobes. When everything is working right with these muscles, they allow both eyeballs to move together in the same direction. When both eyeballs are aligned and move together, we see only one image and have depth perception.

[If the child has an extraocular muscle imbalance such as strabismus, exotropia, esotropia, or crossed eyes, take time now to discuss it. Is the child's problem due to damage to the frontal lobes, which control the coordinated movements of the extraocular muscles? Is one muscle shorter or longer than normal, upsetting the muscular balance? Is the imbalance the result of another disorder? For example, reduced vision in the right eye may cause it to wander and not move in conjunction with the left eye. Abnormal muscle tone in children with cerebral palsy can also affect the extraocular muscles, thereby affecting eye movements. If appropriate, discuss the treatment approach recommended by the doctor such as patching, eye drops, optical aids or surgery.]

[To aid in describing the information contained in the next part of this discussion, point out the structures being discussed using Diagram V-2, "The Human Eye."]

There is a very thin clear membrane, with tiny, very thin blood vessels, that starts at the inside edge of the eye lids, runs along the inside surface of the eye lids, then fold back over and covers the outside front of the eye ball. This is called the conjunctiva. This helps protect the eye from infections and keeps anything from slipping behind the eyeball. It also makes fluids that lubricate the eye. If the conjunctiva becomes infected, it may become pink. This is what we call "pinkeye".

The human eye is oval in shape. This means it is shaped more like an egg and not a ping-pong ball. In an adult, the eye is about 1 inch across. A child's eye is a little smaller.

The eyeball has three layers to it. Most of the outside layer of the eye is called the sclera. It is also known as the "whites of the eyes". The sclera is made up of fibers that criss-cross each other, making the sclera very tough. Since the sclera is tough, it makes a protective coat for the eye protecting everything else inside it. It also keeps light from entering the eye except at the front of the eye.

At the front of the eye the sclera becomes clear so that light can enter the eye. This clear area of the outermost layer of the eye is called the cornea. If you look at someone's eyes from the side, you can see a clear bulge, or bubble, at the front of the eyes. This is cornea.

Because the surface of the cornea is curved, it helps to bend and focus the light entering the eye onto the retina at the back of the eye. This bending of light is called refraction and the cornea refracts 80% of the light being refracted on its way to the back of the eye. If the curvature of the cornea is too steep, not steep enough, or irregular, it does not allow the light to focus, forming a clear image on the retina at the back of the eye. We will discuss the retina a bit later. These may cause or help cause the "refractive errors" we call near sightedness, far sightedness, and astigmatism. In most cases, glasses and contact lenses are all that is needed to correct these errors.

The cornea is also the only part of the eye that can be transplanted, an operation that is less successful in young children.

[If the child has a refractive error or a problem with the cornea, discuss it. High refractive errors are associated with some syndromes such as Down syndrome. Disorders related to the cornea are corneal dystrophy, keratoconus and herpes.]

Behind the cornea is a space called the anterior chamber. It is filled with a liquid called the aqueous humor. We will discuss more about the anterior chamber and the aqueous humor a little later.

Behind the cornea and the anterior chamber is a round ring shaped part of the eye called the iris. This is the part of the eye we refer to when we say that a person has blue, green, hazel, brown - but not black! - eyes. The iris is part of the middle layer of the eyeball.

Just as our skin has pigmentation which gives it color, the middle layer of the eye, which includes the iris, also has pigmentation which gives the eye its color. The amount of pigmentation determines the color of the eye. An iris with a lot of pigment is brown. An iris with a small amount is blue. People with certain types of albinism have little or no pigmentation, that is why most people with albinism have very blue (and almost pink) irides. (Irides is the plural of iris.)

As we learned earlier, the iris is shaped like a ring with a hole in the middle. This hole is called the pupil. The pupil is actually an opening that lets light pass on through to the retina at the back of the eye.

The purpose of the iris is to control the amount of light entering the eye through the pupil. The iris does this by getting wider, making the pupil smaller, or by getting thinner, making the pupil larger. In dim light, the iris gets thinner, or dilates, making the pupil larger allowing more light to enter the eye. In bright light, the iris get wider, or constricts, making the pupil smaller, keeping too much light from entering the eye. Just as there are six extraocular muscles outside the eye that moves it, there are two muscles inside the iris that allows it to dilate or constrict. [Use your hand with fingers and thumb forming a circle to demonstrate constriction and dilation or have the parents watch pupils in a mirror as you shine a penlight in their eyes, then remove it. Remind them of what it is like when they walk from a dark movie theater into the sunny outdoors and vice versa.]

[Disorders related to the iris are aniridia, coloboma and albinism. Also, the pupillary response in some neurologically impaired children may be slow or unequal because of damage to the brainstem which controls this involuntary reflex. These children have difficulty adapting to changes in lighting. For example, if the pupil is fixed large and open, the child may be very light sensitive. Or if the pupil is fixed small and nearly closed, the child may have trouble at night and in dark rooms. Some children may have "hippus" where the pupil dilates and constricts continually, meaning they have little control over the amount of light entering the eye. An abnormal pupillary response may also be caused by medication.]

The iris is connected to another part of the middle layer of the eye called the ciliary body. The ciliary body is made up mostly of muscle and blood vessels. The ciliary body is connected to the lens by thin strands of fiber called suspensory ligaments or the Zonules of Zin. The muscles of the ciliary body pull on the suspensory ligaments, which in turn pull on the lens which allows the lens to change shape. We will discuss more about this a little later today as well as in the future during another lesson.

The ciliary body also has another function. It also produces a watery fluid, the aqueous humor. We will discuss what this fluid does in a little bit.

The rest of the middle layer of the eye is the choroid. It starts at the ciliary body, going all the way around the inside of the eye and back to the ciliary body again. Along with the iris and ciliary body, the choroid is part of the vascular, or blood carrying, layer of the eye. The choroid provides oxygen and nutrients to the retina, the inner most layer of the eye, keeping it alive.

Before we talk about the innermost, and last layer of the eye, we need to go back and talk about the eye's lens. The normal lens in a child has no color and is almost transparent.

It is made up of layers, like an onion, and is very flexible. It is encased in a clear "skin", that helps the lens keep its shape.

As we discussed above, the lens is connected to the ciliary body by the suspensory ligaments. As the muscles of the ciliary body change shape, they tug or let loose of the suspensory ligaments, which, in turn, changes the shape of the lens so the eye can focus on objects both near and far. Along with the cornea, the lens is also responsible for a lot of the refractive power of the eye. We discussed this term earlier today when we talked about the cornea. Unlike the cornea, however, the lens can change shape, fine focusing the light onto the retina depending on the distance of the object at which we are looking. If it needs to focus the image of an object far away onto the retina, the lens will become somewhat "fatter and shorter". If it needs to focus the image of an object close up onto the retina, the lens will become somewhat "thinner and longer". A young child's lens is much more flexible than an adult's. When a low vision child brings objects very close to his face, it is a natural way for him to magnify the images, making it easier for him to see them.

[If the child has cataracts or is aphakic, discuss this and go over the treatment recommended by the eye doctor.]

At the back of the eye is the innermost layer of the eye, the retina. It is a very thin tissue made up mostly of nerves and special cells, somewhat like nerve cells, called photoreceptor. There are two types of photoreceptor cells: rods and cones.

The cones are connected almost one-to-one to the nerves in the retina. The cones give us the ability to see fine detail and color. They work best in daylight or in high lighting. Although cones can be found throughout the retina, most are concentrated tightly in the middle back part of the retina called the macula or central retina. Since most of the cones are concentrated in the macula, we use the macula part of the retina to see fine detail and color. That is why the macula is in the middle back part of the eye. In the very middle of the macula is an area called the fovea centralis. The eye sees the sharpest detail here. [Disorders related to the macula area of the retina include Stargardt's Disease and other types of juvenile macular degeneration; albinism; macular hypoplasia and a few types of retinitis pigmentosa. Discuss these disorders if appropriate.]

The rods are connected 20 or more per nerve. They work best in minimum lighting. Although rods can be found throughout the retina, they are concentrated on the rest of the retina away from the macula, the peripheral retina. The rods provide us with the ability to see gross forms and movement. [Disorders related to the peripheral area of the retina include glaucoma and retinitis pigmentosa. Discuss these disorders if appropriate.]

The rods and cones work as a team in the retina. They answer the questions "Where?" and "What?" when we see. The movement of something or someone is best picked up by the rods located in the peripheral part of the retina, our peripheral or "side" vision. This causes a reflex that turns our eyes towards the source of the movement (Where?) so that the image of that something or someone falls on the cones located in the macular, the central part of the retina, in order to identify that thing or that person (What?).

There is a very thin layer of cells with pigment of the retina that touches against the choroid layer of the eye. This thin layer is called the pigment epithelium. (This structure is not labeled on Diagram V-2, "The Human Eye".) The "feet" of the rods and cones come in contact with the pigment epithelium. Light entering the eye and striking the pigment epithelium bounces back against the rods and cones. Light sensitive chemicals found here changes the light into neural, or "electrical", signals which are then sent back to the brain through the optic nerve.

The pigment epithelium and rods/cones layers of the retina lay next to the choroid and get their oxygen and nutrients from the choroid. If the retina should separate from the choroid, the rods, cones and pigment epithelium would eventually die and vision will be lost in that area.

[There are many other disorders related to the retina such as retinal detachment, retinopathy of prematurity, and retinal coloboma. Discuss these disorders as appropriate at this time.]

All the nerve endings from the rods and cones come together at the back and slightly to one side of the eye to form one big bundle called the optic nerve. At this place there is a slight depression in the retina called the optic disc. Only nerve fibers and blood vessels entering and leaving the eye are present at this spot. There are no rods or cones in this disc, therefore, there is one part of the back of each eye that is "blind", that has no vision. This is called the "natural blind spot" or "physiological blind spot". Sometimes the Latin word scotoma is used for the words blind spot. Most of us have never noticed the blind spot of each eye because each eye covers for the other's blind spot. [Do the exercise described on Diagram V-3, "The Natural Blind Spot," which lets the parents experience their own natural blind spot in each eye.]

When the eye doctor looks into a child's eyes with certain instruments, he will become concerned if the disc is a pale color rather than a healthy red. The color and shape of the disc can indicate the health of the optic nerve tract (or even alert the doctor to the possibility of a brain tumor).

Before we continue along the optic nerve and leave the eye itself, we still need to talk about two other things found inside the eye: the aqueous humor and vitreous humor.

Earlier, we discussed that along with changing the shape of the lens, the ciliary body also produces a watery fluid called the aqueous humor or aqueous fluid. Humor is a Latin word that means "water". The aqueous humor provides oxygen and nutrients to the lens and the cornea which do not have blood vessels within them. The aqueous fluid also bathes these parts of the eye and keep them clean and free of infection.

The ciliary body constantly makes aqueous fluid. The aqueous leaves the ciliary body and enters a small area between the front side of the lens and the back side of the iris called the posterior chamber. It continues to flow across the front of the lens and out through the pupil, which is the opening in the iris, into the large space between the front side of the iris and the back side of the cornea called the anterior chamber. Since aqueous is constantly being made, it has to leave the eye somehow. It does so through a little sieve-like opening called the trabecular meshwork. The trabecular meshwork is found where the inside edge of the cornea and the outside edge of the iris come together. The aqueous drains through this trabecular meshwork into a "tube" called the Canal of Schlemm. This carries the aqueous to veins which then carry the aqueous out and away from the eye. [Glaucoma is a disorder that relates to these structures and the flow of the aqueous.]

The entire area between the back of the lens and the retina is filled with the vitreous humor or vitreous fluid. The vitreous is clear and jell-like. Like air does to a basket ball, the vitreous keeps the eye round. Without the vitreous, the eyeball would collapse.

[Refer to Diagram V-4, "Optic Nerve Pathway In the Brain," for the remainder of this topic.] The optic nerves leaving the back of both eyes come together at a point, just in front of the brain itself, called the optic chiasm. At this point, some fibers in the optic nerve from the right eye "cross over" and join some fibers from the optic nerve of the left eye and, together, go on to the left side of the brain. Likewise, some fibers from the left optic nerve "cross over", joining some fibers from the right optic nerve and, together, they go on to the right side of the brain. We will discuss this again later when we get to Topic 2: How the Visual System Works.

Each bundle of nerves continue, one along the right side and the other along the left side of the brain, to points on each side of the brain called lateral geniculate bodies. These can be thought of as control towers which direct traffic (messages) from the eyes to where they need to go.

Eighty percent of the information goes to an area in the back of the brain called the visual cortex. The visual cortex is the part of the brain that interprets the signals traveling along the optic nerves. The visual cortex is divided in half between the left and right occipital lobes.

The remaining twenty percent of the information goes to the brainstem which controls involuntary visual functions such as eye blinks and the changes in the size of the pupils.

Disorders related to the optic nerve tract are optic nerve atrophy, optic nerve hypoplasia, hydrocephalus, and tumors putting pressure on the nerves and thereby damaging them.

A doctor once said, "The eye doesn't know a horse from a barn. It is the brain that sees." The eye is connected via the optic nerve to the visual cortex of the brain. It is this special part of the brain which forms a picture from information collected by the retina. The visual cortex in turn sends information to other areas of the brain which process and respond to it. For example, when you read your name, the frontal lobe causes the extraocular muscles to move, which causes the eyes to move during reading; the visual centers in the brain process information about the line configurations and shapes; the language centers of your brain help you identify your name; motor, language, and auditory centers help you say it and so on. Hundreds of pieces of information are being shared and processed in seconds. There are more interconnections between the visual cortex and other areas of the brain than between any other sense area and other areas of the brain. The visual system provides the brain with 75% of its information. [The eye disorder related to this part of the visual system is cortical visual impairment.]

In our next topic, we will discuss how the visual system works. We will refer back to this topic any time we need to do so.

SAMPLE ACTIVITIES

1. Use the activities suggested in the Sample Discussion (pupillary response, natural blind spot activities).

2. Show and discuss a simple book on the visual system (e.g., Your Eyes, Chapter 1, see Reference and Reading List below) or an article or chapter on the visual system which could be obtained from the early intervention program or a local library.

SAMPLE CHALLENGES

1. Read through this article (chapter or book) on the eye.

2. Go to the library and find additional information to read about the eye and the visual system.

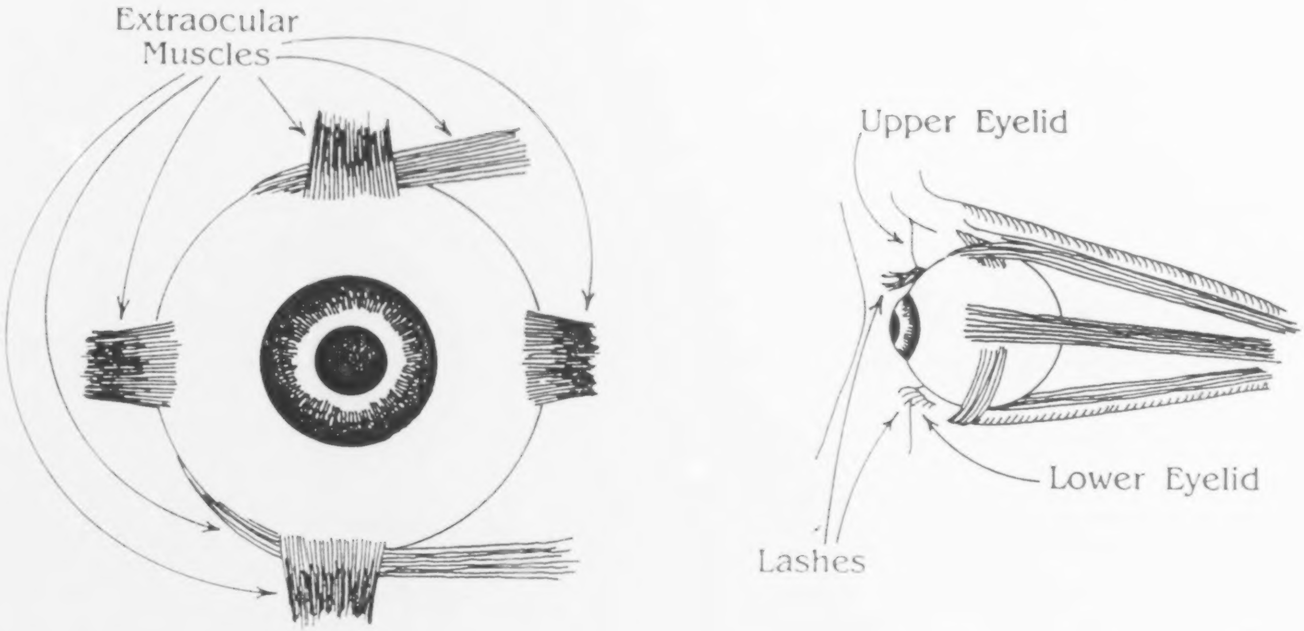
REFERENCE AND READING LIST

1. Hanson, M. (1988). Beyond tracking: Enhancing vision development from birth to one year. Vision Unlimited, PO Box 1591, Bridgeview, IL 60455.
2. The human eye. (1986). Southbridge, MA: American Optical.
3. Chalkley, T. (1974). Your eyes. Springfield, IL: Charles C Thomas.
4. Smith, A. J. & Cote, K. S. (1982). Look at me: A resource manual for the development of residual vision in multiply impaired children. Philadelphia, PA: Pennsylvania College of Optometry.
5. Goldberg, Stephen, M.D. Ophthalmology made ridiculously simple. Miami, FL: MedMaster, Inc. 1982.

Diagram V-1

THE EXTERNAL STRUCTURE SURROUNDING THE EYE

RIGHT EYE


Extraocular
Muscles
Upper Eyelid
Lower Eyelid
Lashes

FRONT VIEW
Behind the Eyelids

SIDE VIEW

'81

Diagram V-2

THE HUMAN EYE

(Cut in half and looking from the top downward)

RIGHT EYE

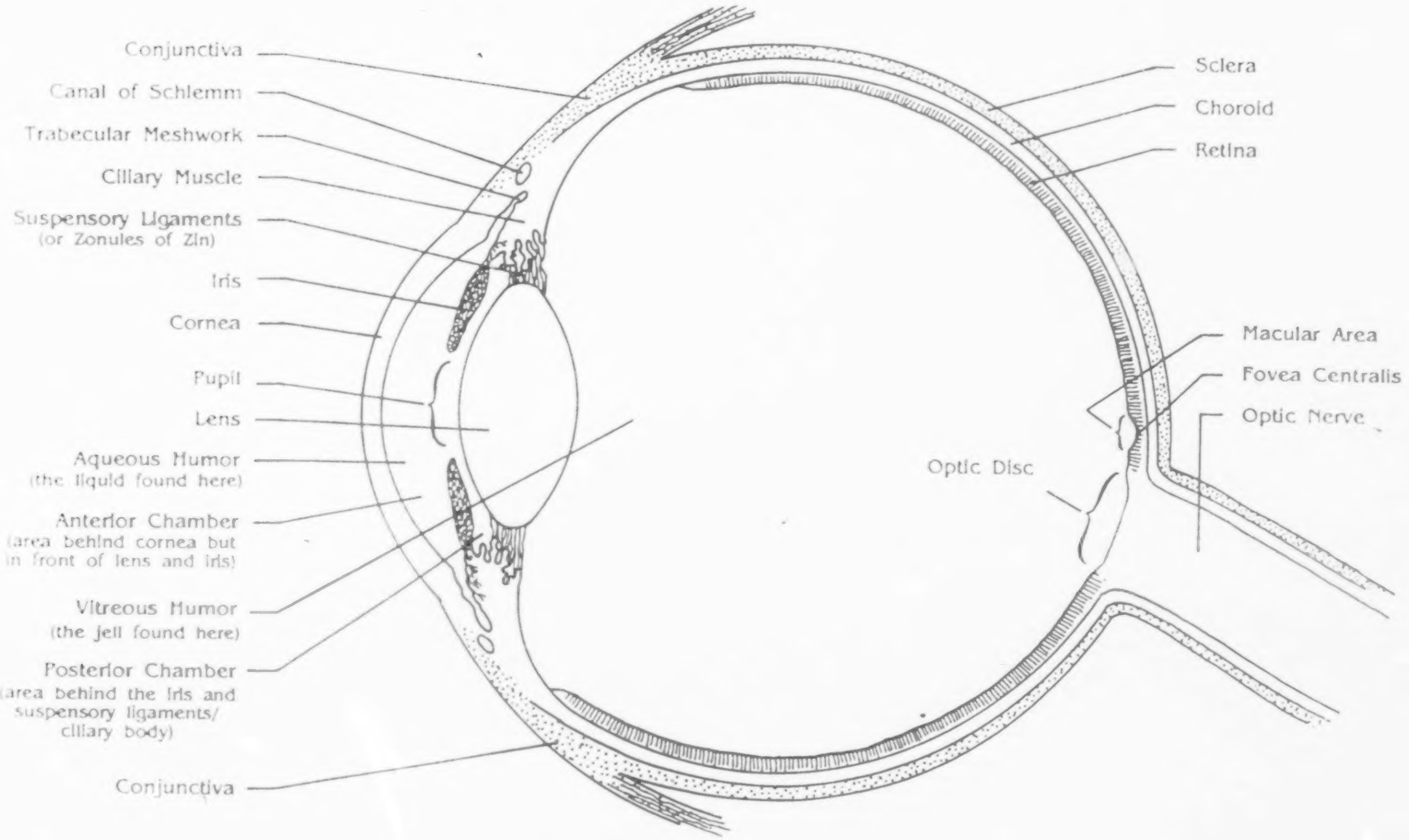
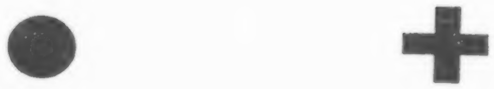

Conjunctiva
Canal of Schlemm
Trabecular Meshwork
Ciliary Muscle
Suspensory Ligaments
(or Zonules of Zin)
Iris
Cornea
Pupil
Lens
Aqueous Humor
(the liquid found here)
Anterior Chamber
(area behind cornea but in front of lens and iris)
Vitreous Humor
(the jell found here)
Posterior Chamber
(area behind the iris and suspensory ligaments/ ciliary body)
Conjunctiva
Sclera
Choroid
Retina
Macular Area
Fovea Centralis
Optic Nerve
Optic Disc

Diagram V-3

THE NATURAL BLIND SPOT

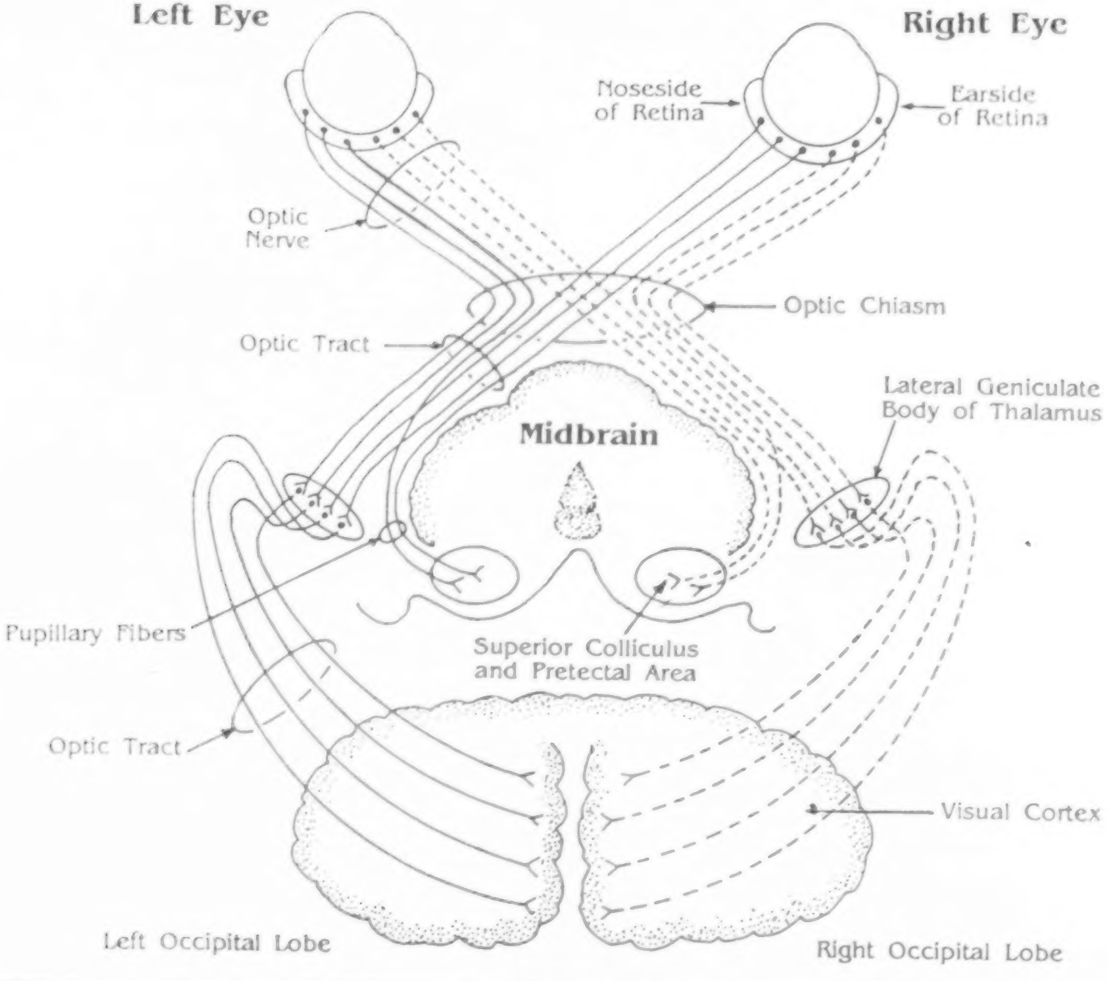


Hold this page at arm's length, and close your left eye. Stare hard, with your right eye at the dot. Move the page slowly towards you – still staring at the dot. What happens to the cross?

Try the experiment again, but with your right eye closed. Stare with your left eye at the cross – then start moving the page slowly toward your face. What happens to the dot?

Diagram V-4

OPTIC NERVE PATHWAY IN THE BRAIN


Left Eye
Right Eye
Noseside of Retina
Earside of Retina
Optic Nerve
Optic Chiasm
Optic Tract
Lateral Geniculate Body of Thalamus
Midbrain
Pupillary Fibers
Superior Colliculus and Pretectal Area
Optic Tract
Visual Cortex
Left Occipital Lobe
Right Occipital Lobe

TOPIC 2: FUNCTION OF THE VISUAL SYSTEM

GOAL

Parents and other caregivers will understand how the visual system works and relate this to the child's vision problem.

MATERIALS

- Diagram V-5, "Light Rays And How They Are Bent In The Eye"
- Diagram V-6, "Normal Visual Field"
- Diagram V-7, "Accommodation of The Lens"
- Diagram V-8, "Ambiguous Figures"
- An eight to 10 foot length of thin rope
- Prism
- Clear glass of water and a pencil
- Piece of paper with a lot of print on it

INSTRUCTIONS TO EARLY CHILDHOOD SPECIALIST

Adapt and simplify this topic for parents and caregivers who are not as interested in how the visual system works. Relate the information to the child's own vision problem as much as possible. For example, when talking about how light is bent and focused on the retina, talk about how the child's refractive error is being corrected if the child has this problem. Or, when talking about how the eye moves, point out how the child's muscle imbalance affects those normal movements.

If needed, go back over any points in the Sample Discussion section of the previous topic, Anatomy of the Visual System. If the parents should forget names, locations, or functions of any part of the visual system that is related to their child's vision problem, encourage them to review the needed information in the previous topic.

SAMPLE DISCUSSION

In order to see, we need light. The eye is the sense organ that receives rays of light that reflect off of objects that we see. The eye then changes those light rays into electric, or neural, signals and sends them on to the brain for interpretation. From the patterns of light rays striking against the retina and the storehouse of past experiences recorded in our brains, we perceive a world of colorful objects and living things in three dimensional space.

Light rays travel in waves. Scientists have found that the rays of light for each of the colors we see--red, orange, yellow, green, blue and purple--travel at different frequencies. A frequency is how many cycles, or "waves", per second a ray of light has. [Use the length of rope to demonstrate light frequency and what is meant by a low frequency verses a high frequency. Have a parent or someone else hold one end of the rope, or tie it to a chair or door handle. You take the other end of the rope. For the purpose of this demonstration, only shake the rope up and down.] This length of rope will show us how light travels and what I mean by frequency. As I shake this rope, you can see the "waves" traveling from my end of the rope to the other. Light travels in much the same way. You can see that the waves go up and down, like peaks and valleys. From the top of the peak of one wave to the top of the peak of the next wave, is one cycle. [Shaking the rope slowly, continue by saying:] Right now I'm shaking the rope slowly. The distance from the peak of one wave to the peak of the next is long. The waves are traveling slowly. Not many waves or cycles are traveling from my end of the rope to the other. This is a low frequency. [Increasing the shaking of the rope...] You can see that as I shake the rope faster and faster, the distance from the top of one peak to the top of the next is getting shorter and shorter. The waves or cycles are traveling more quickly. This is a higher frequency.

The light rays of each color travels at a different frequency. Violet and blue light have the highest frequency. They have the quickest, shortest cycles or waves. Yellow and red light rays have the slowest, longest cycles or waves.

Sunlight is all the frequencies of light combined together. We can see this with the help of a prism. [Show the parents how light which passes through a prism is broken into the various colors.] When sunlight hits a prism, it breaks up into each of the different colors of the rainbow. You can see that violet and blue are at one end and yellow and red are at the other. Red light has the lowest frequency and violet has the highest. There is a form of light that travels slower than red light and faster than violet, which our eyes cannot see.

During our discussion for our last topic, Anatomy of the Visual System, we discussed that the part of the retina called the macula had a high concentration of cells called cones. Cones are the cells in the retina that can best tell the difference between the different frequencies of light. The cones are the cells responsible for seeing color. Have you ever wondered why babies start out preferring bright colors such as red and blue instead of soft pastel colors? It is thought that the cone cells responsible for seeing brighter colors are the first to fully develop.

As billions of light rays travel through the air, they bump into objects such as the furniture in your house, my book--just about everything. Like all objects, my book absorbs some of the waves of certain frequencies of light and reflect other waves of certain other frequencies. As you look at my book, the light rays reflected back in different patterns enter our eyes and strike and stimulate the retina. The patterns of light reflected by my book are different from those reflected by the different furniture in this room. This allows the brain to tell the difference between my book and, let's say, the chair where I am sitting. Different objects--people, plants, animals and buildings--look different or similar depending on the patterns of light reflected from them as well as our past experiences with these objects.

It is also very important to know that light rays bounce off objects in all directions. Remember this because we will discuss this more in just a little bit.

As light enters the eye, it is refracted, or bent, as it passes through the cornea, the lens and the fluids in the eye. This happens because as light rays pass from one clear substance, in this case, the air, into a more dense substance, such a water, the light rays slow down a little bit and change direction. [Demonstrate this by putting a pencil in a glass of water.] Look what happens to the image of this pencil as the rays of light from it travel through the water. When you look at the pencil from the side, the pencil appears to bend. The light rays bouncing off the pencil have been refracted, or bent.

Let's follow the path light takes as it enters the eye. (Show and refer to Diagram V-5, "Light Rays And How They Are Bent In The Eye".) As light rays enter the curved surface of the cornea, they are bent towards the pupil and the back of the eye. They are bent even more by the aqueous fluid and then by the lens of the eye. The light rays are also bent by the vitreous humor as well. All of these--the cornea, the lens and the fluids in the eyes--work together to focus the light rays into a clear image on the macular area of the retina on the back of the eye. Notice in the picture here that the image is upside down on the retina. This happens when the light rays go through the lens. The image is put back right-side-up by our brain.

Both of our eyes working together can see things in a large area above, below and to the sides of our eyes. The area we can see is called a visual field. From our far left to our far right, this area or visual field, ranges from about 160 - 180 degrees. (Show Diagram V-6, "Normal Visual Field".)

Let's do a little demonstration now. (Give the parents the piece of paper with writing on it and have them hold it out to the sides of their heads as they look straight ahead at you.) What are you visually aware of about the paper you are holding? Can you read anything on it? No? That is because the light rays bouncing off it and into your eyes are landing on the periphery or outside edges of your retina. Can you remember what kind of receptor cells are in this part of the retina and the information they give you? These are the rods. They give gross form, awareness, and movement information. This peripheral vision is what enables you to avoid all the toys on the floor as you run to grab the stool your baby is about to pull over on himself.

Now, slowly move the piece of paper around to the front of your eyes until you are able to read it. The light rays reflecting off the print on the paper are now entering the eye in such a manner that they are focused on the macula area of the retina. Can you remember what kind of receptors cells are found there and the role they play? These are the cones. They allow us to see fine detail and color. Actually, your eyes are only able to read a small area of print. The surrounding print is blurry. This is because, as we discussed earlier, the area on the retina that gives us our finest vision is very small, like a pinpoint.

[For this next paragraph, show Diagram V-7, "Accommodation Of The Lens".]

Not only does the position of an object in relation to the eyes, to the sides or straight ahead, determines how our eyes have to adjust in order to see areas clearly, but also its distance from the eyes. Pretend you are looking at a tree 20 feet or more away. Remember a few minutes ago I said that light rays bounce off objects in all directions? These rays are traveling away from each other. We call this diverging rays. When an object is 20 or more feet away, the only light rays that are coming towards our eyes from that object, in this case, the tree, are all traveling in the same direction--they are parallel. All the others have traveled in different directions quite a distance from the eye. Since the light rays from the tree are already traveling in a parallel fashion, they do not have to be bent much to be brought into focus on the retina. Therefore the lenses in your eyes are relaxed and are flatter in their shape.

Now pretend that you are looking at one leaf on the tree as you are walking closer to it. The leaf appears to be getting bigger. Try this with some real object in this room. [Pause and let the parents do this.] This is because the image of that object is taking up more and more of your visual field and stimulating a larger and larger area on your retinas. The rays now entering your eyes from that object are no longer parallel. They are diverging, or moving out in all directions. The lenses in your eyes now must bend those diverging rays of light so that they travel in the same direction towards the back of your eyes and the retinas. The lenses now have to become "fatter" to bend or refract those light rays.

This process of the lens changing shape to keep objects in focus at both near and far distances is called accommodation. Accommodation happens so quickly we are not aware of it. Try glancing around the room at different objects at different distances, including some very close and some very far away. Think about how quickly your lenses are accommodating to keep things in focus. Here is another exercise to try: Hold two fingers of one hand at arm's length in front of you. Focus on those two fingers and notice how blurry the distant background is. Now, focus on an object across the room as you look past your fingers. How do your fingers appear now? (Hopefully, blurry. The parents may say it looks like they are holding up three fingers instead of two.)

When following an object as it moves closer to you, both of your eyes must begin to turn in equally towards each other and the nose. We call this convergence. As you follow the object back out as it moves away from your face, your eyes move apart or diverge. Watch my eyes as I demonstrate this. (Do this so that the parents can see the movements of convergence and divergence.)

Your eyes are never completely still. When they are searching for something they move together in small rapid jerks called saccades. (Let the parents observe this as you visually search and scan the environment.) When I am watching something move, or tracking, notice how my eyes move more slowly. When my eyes are focused on something like that picture on your wall, my vision will start to fade after a few seconds. My eyes have to repeatedly sweep the image of that picture over the receptor cells on my retina so that those cells do not start to adapt and cease sending a signal of the image of that picture to the back of my brain. What is so amazing is that in spite of all the little eye movements, the saccades, the picture does not appear to be moving! Now you try this.

The eyes are slightly separated so that each one sees the world from a slightly different angle. Point to a small object on the wall or on a table, looking at it with both eyes. Keep your finger in the same position as you close your right eye, then quickly open it while shutting your left eye. Continue switching back and forth between your eyes. Did you notice anything? (The object and finger shifted position back and forth.) The brain uses this slight difference between the images of each eye along with other clues to give us depth perception which is also called binocular vision or stereo vision. Depth perception is the ability to judge distances so that we can do such things as reach for and grasp an object, react in time to keep from getting hit by a flying object or to parallel park a car. Close one eye and reach for a pencil on the floor as you use your open eye to do the reaching. What did you experience?

It has often been said that children with monocular vision, which is usable vision in only one eye, do not have depth perception. This is not quite true. These children may have difficulty with some tasks requiring depth perception, such as reaching, climbing steps or catching a ball, but many of these children have found ways to get around this. Their brains, like ours, learn to use experience and other clues for judging distances. Some of these clues are:

1. Relative size: objects look smaller the further away they are and bigger the closer they are;
2. Shadows which are cast by the objects;
3. Brightness;
4. Clarity: close objects are in sharper focus; and
5. Motion of the objects.

Up until now, we just talked about how the eyes move, how large of an area they can see, and so on; but now let's discuss what happens when light rays strike and stimulate certain areas on the retina.

Remember that the receptor cells, the rods and cones, turn the light energy into electrical, or neural, signals which then quickly travels along the optic nerve path. (Use Diagram V-4, "Optic Nerve Pathway In the Brain" from Topic 1 as you discuss the optic nerve pathway.) At the chiasm, where the two optic nerves meet, some of these signals, or messages, cross over to the opposite optic nerve while others stay on the same side. On their way from the chiasm to the brain, the nerves along the optic tract pass through a relay station on each side of the brain called the lateral geniculate bodies. Here, the signals are divided up and sent to different areas of the brain.

Eighty percent of the signals and information goes to an area in the back of the brain called the visual cortex. The visual cortex is the part of the brain that interprets the signals traveling along the optic nerves. The visual cortex processes the information about the form, brightness, color, size distance, depth, lines and edges of the object being seen. All of this is put together into an image that we see. The visual cortex then sends this image to other areas of our brain which in turn help us to recognize, name, interpret and use the information provided by the visual system.

Seeing, or visual perception, involves many sources of information beyond those which meet the eye. It involves knowledge of an object or person that we get from previous experience which include touching, smelling and hearing the object or person. For example, your baby comes to know you over time because of all the different things you have done with him. He has come to know your touch, your smell and your voice.

During visual perception, or seeing, your brain is actively looking for the best way to make sense out of what it sees when looking at an object. Along with the image being formed in the visual cortex, your brain searches its memory of experiences to locate any other information associated with the object. For example, if you turned the TV on and people and animals started coming out of it into your living room, you would think that your TV was not a TV after all. Why? Because based on your past experiences, the thing that looked like a TV would not fit your previous experience about how a TV works; namely, animals and people just do not come out of it!

To show you how active, or dynamic, seeing really is, I have some pictures for you to look at. (Use Diagram V-8, "Ambiguous Figures" and ask the parents what they see in each picture. Then let them read the comments below each picture.) Did you notice how your mind kept trying to figure out the drawings as you looked at them? It tried to compare them to things you know about, searching for the best interpretation or understanding about them.

Does this give you a bit of a feel for how complex the visual system is? In a sense, we learn to see. This becomes crucial when dealing with a child whose visual system is not working quite as it should. To a certain degree, he, too, can learn to put meaning to the blurs and blobs in his world through repeated multisensory experiences with people, things and events he comes in contact with on a daily basis.

We will discuss this later in other topics.

SAMPLE ACTIVITIES

1. Do all the activities suggested in the Sample Discussion.

2. Share a simple book, article or chapter on visual perception checked our from the program or local library (e.g., Your Eyes, Chapters 2 and 9. See Reference and Reading List below).

SAMPLE CHALLENGES

1. Look through this article (book or chapter) about how the visual system works. You may even wish to see if your local library has any useful information on this topic. We can discuss some of the key things you learned from your reading next week.

2. This week think about how your child's visual impairment has affected the normal visual process and what this might tell you about how he sees. Be ready to discuss this during our next home visit.

REFERENCE AND READING LIST

1. Basic optical concepts. (1986). Southbridge, MA: American Optical Company.
2. The human eye. (1986). Southbridge, MA: American Optical.
3. Chalkley, T. (1974). Your eyes. Springfield, IL: Charles C. Thomas.
4. Gregory, R. L. (1977). Eye and brain: The psychology of seeing. New York, NY: University Press.
5. Smith, A. J. & Cote, K. S. (1982). Look at me: A resource manual for the development of residual vision in multiply impaired children. Philadelphia, PA: Pennsylvania College of Optometry.

Diagram V-5

LIGHT RAYS AND HOW THEY ARE BENT IN THE EYE

RIGHT EYE

(Cut in half and looking from the top downward)

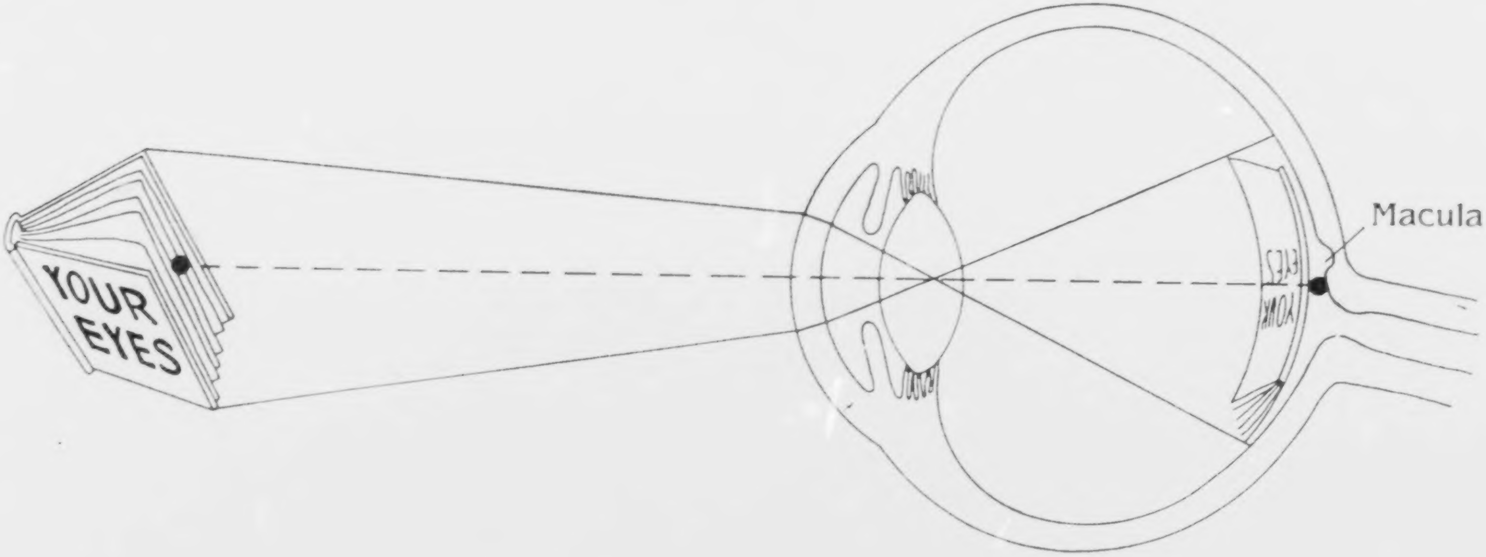

YOUR EYES
YOUR EYES
Macula

Diagram V-6

NORMAL VISUAL FIELD

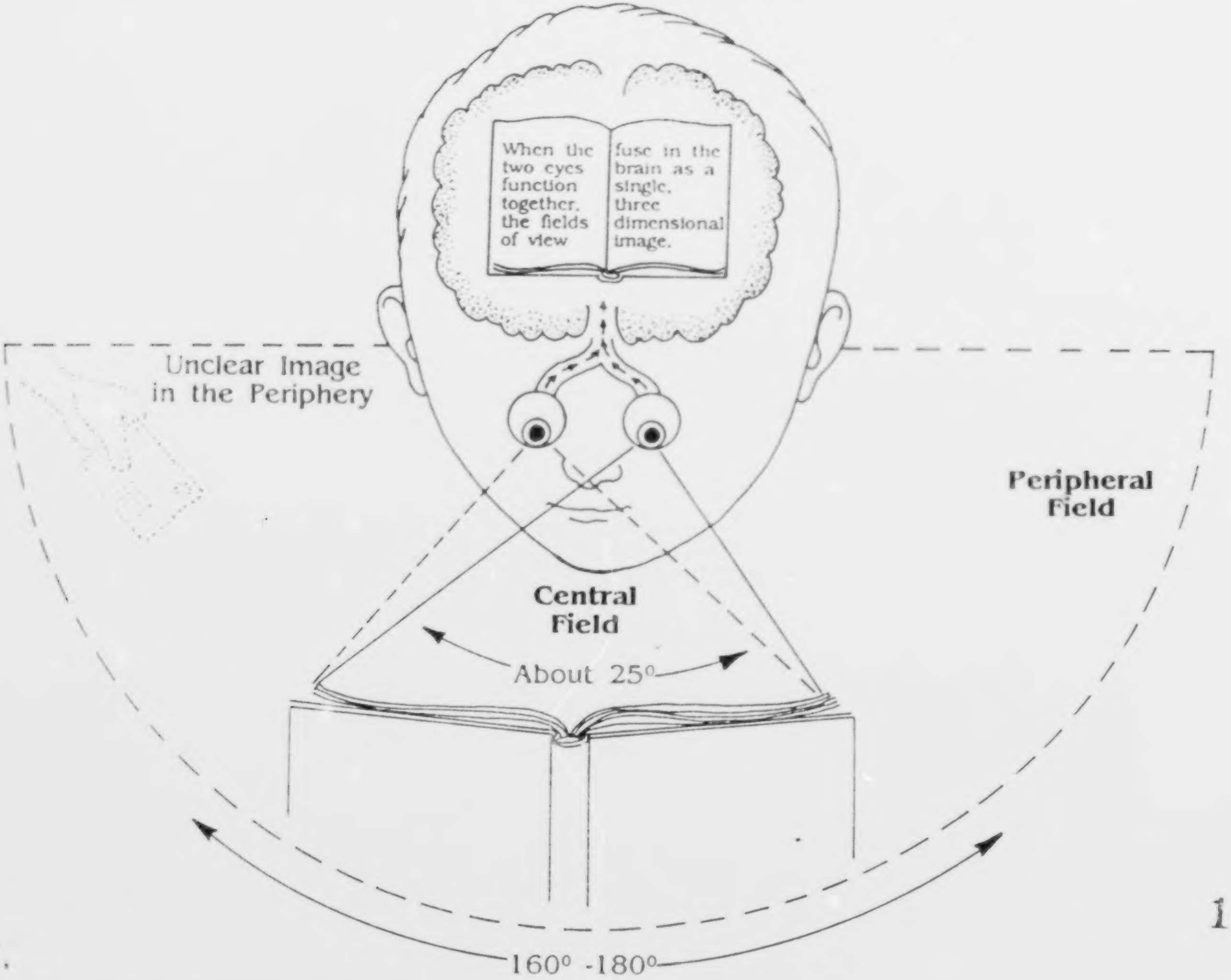
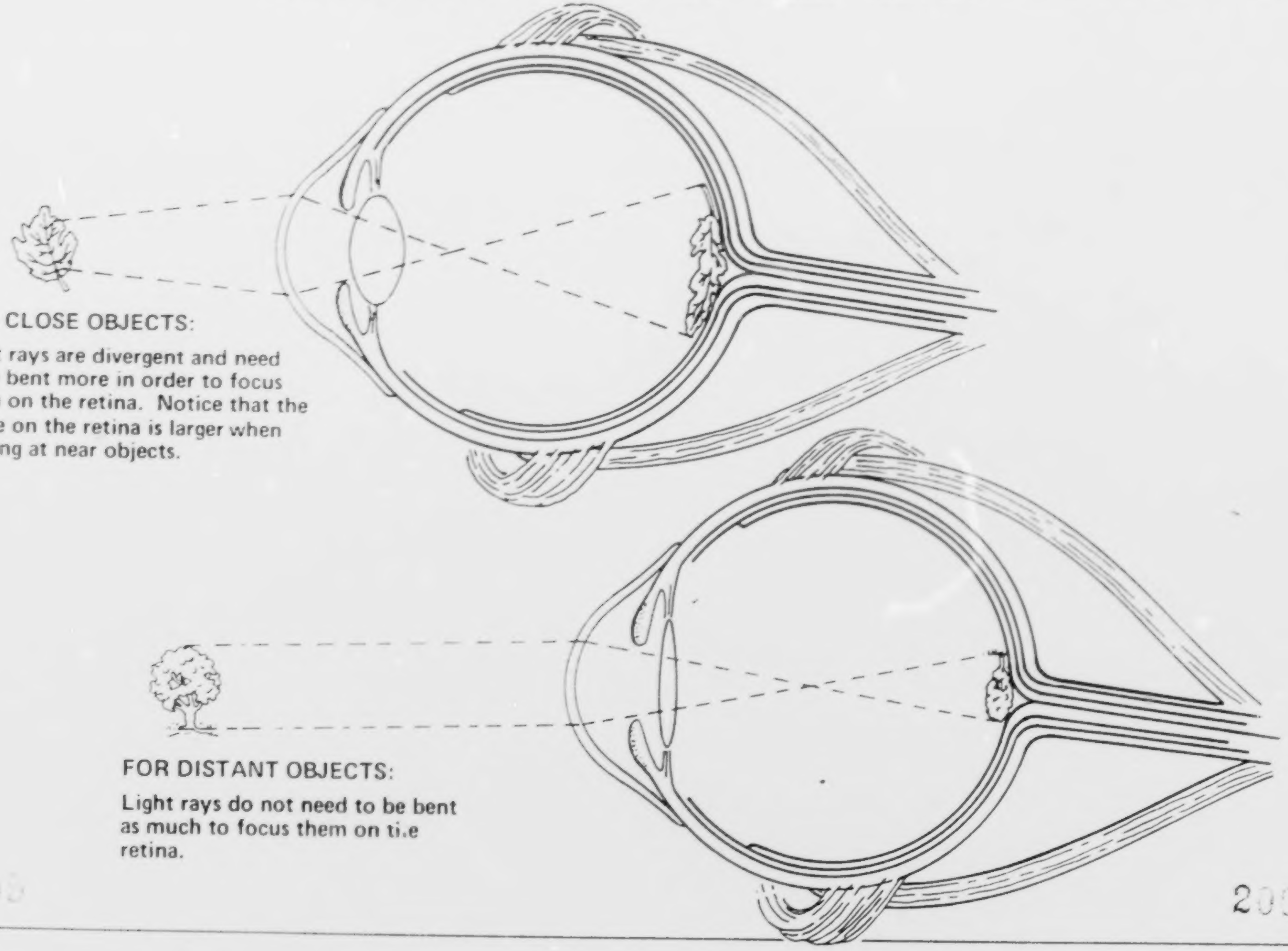

When the two eyes function together, the fields of view
fuse in the brain as a single, three dimensional image.
Unclear Image in the Periphery
Peripheral Field
Central Field
About 25°
160° -180°

Diagram V-7

ACCOMMOCATION OF THE LENS



FOR CLOSE OBJECTS:

Light rays are divergent and need to be bent more in order to focus them on the retina. Notice that the image on the retina is larger when looking at near objects.

FOR DISTANT OBJECTS:

Light rays do not need to be bent as much to focus them on the retina.

What are Visual Acuities and Visual Fields?

What are Visual Acuities and Visual Fields?

Visual Acuities:

Visual Acuity: Is the term used to state how clearly the consumer is able to see the fine detail of an object and at what distance. In short, it states how clearly the consumer sees.

There are two types of visual acuities that are measured:

Far Distance Visual Acuity (often just called "Distance Visual Acuity")
Near Distance Visual Acuity (often just called "Near Visual Acuity")

Doctors in the United States usually record far distance visual acuities in what is called Snellen Equivalents. The numbers - 20/20, 20/200, etc. - all provide usable information. The top number, the numerator, is the distance from the consumer's eye(s) to the target, usually an eye chart. The bottom number, the denominator, is the size of the print or target read/identified.

These numbers can provide a meaningful reference point to help get an functional idea of just what the consumer can see. A consumer with the far distance visual acuity of 20/20, which is "normal" distance vision, sees an object clearly at 20 feet what *should* be seen clearly at 20 feet. If a consumer has the distance visual acuity of 20/70, which is the visual acuity sometimes used to determine "visual impairment", the consumer can see an object clearly at 20 feet that another person with "normal" distance vision (20/20) sees at 70 feet. A consumer who has the distance visual acuity of 20/200, which is the best corrected distance visual acuity used to determine "legal blindness", can see an object clearly at 20 that another person with "normal" distance vision (20/20) sees clearly at 200 feet!

Near acuities indicate how well a consumer can see to perform near, detailed tasks such as reading, sewing, and drawing. Unlike distance acuities which are written in the United states almost solely using the Snellen Equivalent, near visual acuities are recorded in several different ways.

To show the relative size of letters/numbers/targets these various systems indicate, a **Table of Approximate Equivalents of Near Notations** is provided.

Table of *Approximate* Equivalents of Near Notations

Metric Equivalent	Snellen Equivalent	Jaeger Equivalent	Point/N Equivalent	*Approx.* Letter Size	Examples of Test Size
13M	20/640	---	---	18mm	headlines
12M	20/600	---	---	16mm	headlines
10M	20/500	---	---	14mm	headlines, can labels
9M	20/450	---	48 Pt	12mm	headlines, can labels
8M	20/400	J #20	30 Pt	11mm	subheadlines, can labels
6M	20/300	J #19	---	9mm	subheadlines, can labels
5M	20/250	---	---	7mm	subheadlines, can labels
4M	20/200	J #16	27 Pt	5.5mm	subheadlines, can labels
3M	20/150	J #15	24 Pt	4.5mm	"jumbo" large print, can labels, children's books
2.5M	20/125	J #13	20 Pt	3mm	some large print, labels, children's books
2M	20/100	J #11	18 Pt	2.5mm	most large print/most APH books, children's books (grades 1 - 3)
1.5M	20/80	J #10	14 Pt	2mm	children's books.(grades 4 - 7), some magazine print, some hard bound books
1.2M	20/60	J #7	10 Pt	1.5mm	hardbound books, some magazines, and typing (a.k.a., *standard print*)
1M	20/50	J #5	9 Pt	1mm	most paperbacks, some magazines, typing (a.k.a., *standard print*)
.80M	20/45	J #4	7 Pt	.80mm	newspapers, phonebooks, paper backs
.75M	20/40	J #3	6 Pt	.75mm	newspapers, phonebooks, paper backs
.50M	20/25	J #1	4 Pt	.50mm	fine print, phonebooks, stock market pages, want ads, footnotes
.37M	20/20	J #1+	3 Pt	.30mm	this is extremely fine print

Prepared by Larry Rhodes, 31 May 1989, updated 20 January 1995

Samples of *Approximate* Point and Metric Print Sizes

This text is in 6 Pt/.75M print

This text is in 8 Pt/1M print

This text is in 10 Pt/1.2M print

This text is in 12 Pt/1.25M print

This text is in 14 Pt/1.5M print

This text is in 18 Pt/2M print *

This text is in 24 Pt/ 3M print

This text is in 36 Pt/ 7M print

This text is in 48 Pt/ 9M print

* Most books produced by the American Printing House for the Blind (APH) are printed in 18 Pt/2M print.

Prepared by Larry Rhodes, 20 January 1995
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Visual Fields:

Visual Fields: A functional definition of visual fields is the total area a person can see - above, below, to the sides, and straight ahead - while looking straight ahead and keeping the head and eyes still.

Any area in the visual field where there is missing or distorted vision is called a blind sport or *scotoma* (pl. *scotomas* or *scotomata*)

The Five Types of Vision Loss

The Five Types of Vision Loss

Visual problems are the result of one or more of the following areas of visual functioning:

Visual acuity: The consumer does not see as clearly as she/he should; images are not sharp

Visual field: The area the consumer can see - above, below, to the sides, and straight ahead - is limited when holding her/his head and eyes still

Contrast sensitivity: The consumer is unable to see the relative difference between the lightness and darkness of objects (something like looking at a faded photograph)

Ocular motor control: The consumer has difficulty moving her/his eyes when visually fixating, following, and/or scanning objects

Visual processing: The consumer's brain is having difficulty making sense out of what she/he is seeing

INSITE RESOURCES FOR FAMILY CENTERED INTERVENTION FOR INFANTS, TODDLERS, AND PRESCHOOLERS WHO ARE VISUALLY IMPAIRED

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TOPIC 3: HOW VISION IS AFFECTED

GOAL

Parents and other caregivers will know the implications of the child's eye disorder(s), including how the child sees and the treatment recommended for the disorder.

MATERIALS

- Diagram V-9, "The Eye Compared To a Video System"
- Diagram V-10, "How Visual Losses Appear"
- Diagram V-11, "Different Problems That Can be Found in the Optic Nerve Pathway With the Resulting Visual Field Loss"
- Diagram V-12, "Normal Gazes"
- Diagram V-13, "Heterotropia or Strabismus"
- Diagram V-14, "Vision is More Than 20/20 Eyesight" (copies of this, in groups of 500 cards, can be purchased from Optometric Extension Program, 2912 South Daimler Street, Santa Anna, CA 92705)
- Low vision simulators, one of which is similar to the child's visual loss. (If the child has both hearing and vision problems, be sure to add earplugs and headphones.)
- An acuity chart, preferable a Snellen with the big "E"

INSTRUCTIONS TO EARLY CHILDHOOD SPECIALIST

Because of the importance of this topic, it may be helpful to spend at least a couple of weeks on it. Know ahead of time if the child's ocular disorder has resulted in one or more of the following functional visual problems:

1. Loss of visual acuity - distance and/or near;
2. Loss of visual field;
3. Contrast sensitivity;
4. Oculomotor problems; and/or
5. Visual processing difficulties.

Share the introductory information on the first page of the Sample Discussion. Then, go over the information which relates specifically to the child's ocular disorder and apply it to his specific situation. For example, if the child has cataracts only, the information on acuity and contrast sensitivity loss may be all that applies to him. If the child has brain damage with cerebral palsy and a diagnosis of cortical visual impairment with strabismus, the information on processing and oculomotor disorders will be the most applicable.

When doing activities with the vision simulators for the visual acuity and visual field loss, make sure that you have the parents experience several activities. For example, have them:

1. Walk around or find something upon request;
2. Find an item to order out of a catalog, read a book, do a puzzle, or do some handwork; or
3. Pour a cup of milk or brush their teeth.

Instructions for making low vision simulators are found in Appendix B on page 635. If the child is also physically impaired, try to simulate a physical handicap in some of the activities (e.g., parents can use only one hand, or can have no head control). If the child is also hearing impaired, give a simulated auditory impairment (cotton balls or earplugs may be placed in ears with earphones on top of all of that, or speak very softly or not al all, or use only gestures). When finished with an activity, ask the parents (or caregiver) how it felt and what kinds of things helped or hindered their efforts. Relate their experiences to what it might be like for their child to function with his visual impairment.

SAMPLE DISCUSSION

The visual system - the eyes, the optic nerves, and the brain - can be compared to a video system: the video camera, the cable, and the television set [show parents Diagram V-9, "The Eye Compared To a Video System"]. Of course this analogy is simplistic since both the visual system and the video system are much more complex than shown in this figure.

Many things can go wrong in either system. For example, if the lens on the video camera is scratched, the image on the TV will not come through clearly. If the camera is out of focus, the picture will be blurred. If the cable connecting the video camera and the TV is defective, the signal to the TV will be weak or absent. Problems within the TV itself will also affect the picture on the TV. All the parts have to be working well together for a clear image to appear on the television screen. In the same way, the eye (which collects information), the optic nerve (which carries it), and the brain (which interprets it) must all work together for good vision to occur.

There are numerous things that can go wrong with parts of the visual system, resulting in hundreds of eye problems such as cataracts, retinopathy of prematurity, or strabismus. Most children with vision impairments have more than one eye problem at the same time which then affects how they see in many ways.

Most eye problems fall into one or more of five categories used to describe visual loss. These are:

1. Loss of Visual Acuity: The child does not see as clearly as he should, images are not sharp.
2. Loss of Visual Field: The area the child can see - above, below, and to the sides of his eyes - is limited when holding his head and eyes still; or he may have islands of vision.
3. Oculomotor Problems: The child has difficulty with moving his eyes when fixating, following, and/or scanning objects with his eyes.
4. Reduced Contrast Sensitivity: The child is unable to see the relative difference between the lightness and darkness of objects, something like looking at a faded photograph.
5. Problems with Visual Processing: The child's brain is having difficulty making sense out of what he is seeing.

Remember, most children with vision impairments have problems in more than one of the above areas. For example, a child with retinopathy of prematurity may have visual acuity, visual field and contrast sensitivity losses.

We have had a chance to talk a little about your child's eye problems. Today we want to look more closely at how it affects his vision.

[For discussing each of the five categories used to describe visual loss, refer to Figure 10, "How Visual Losses Appears", as appropriate.]

LOSS OF VISUAL ACUITY

A child who has a loss of visual acuity does not see his world as clearly as he should. Let me show you what I mean. [Conduct an activity with several acuity loss simulators, such as 20/200, Light Perception, and No Light Perception. See Appendix B on page 635 for instructions on how to make or purchase low vision simulators.] As you can see, there are different amounts of loss of visual acuity, and no two children see the world in quite the same way.

There are two types of visual acuity losses--distance and near. If a child has a distance visual acuity loss, distant objects appear blurry. If a child has a near visual acuity loss, near objects appear blurry. A very large number of children who have vision impairments have both losses.

Doctors in the United States usually record visual acuities in what is called Snellen equivalents. Have you heard of the term "20/20 vision"? Well, this is a Snellen equivalent.

[If the child's eye exam resulted in a Snellen acuity measure for the child, use the following explanation. If it did not, do not spend much time on the explanation unless the parents are interested.]

What do these Snellen visual acuity numbers mean? The top number - the first number said, the numerator - tells us how far your child stood from the eye chart when he was tested. The bottom number - the second number said, the denominator - tells us what was the smallest line your child was able to read or identify.

These numbers also mean something else. The big "E" at the top of the standard eye chart is a "200 foot" sized letter. This means that a person with normal, or 20/20, vision can read the "E" at 200 feet - 2/3 of the length of a football field. A legally blind child with visual acuities of 20/200 could read the "E" at only 20 feet away while the person with normal vision could read the "E" at 200 feet away. Some children with vision impairments have visual acuities of 20/400 or 20/800. This means that they could not stand any further than ten or five feet away to read the big "E". A child's visual acuities may be so poor that the acuities can not be written in numbers. Words like "sees shadows and gross forms" or "sees light" are used.

There are some methods that can be used to get an acuity measurement on babies and children who cannot identify letters or pictures on a chart. These include such testing methods as preferential looking using the Teller Acuity cards and the STYCARS Test (see information on second page of Diagram V-16). These tools and methods are still not commonly used by eye physicians. [Note: If parent wants to know more about these, go into the information on them in greater detail.]

It is difficult to measure exact acuities for babies and children who have multiple impairments. That is why you rarely see numbers like 20/100 written on their eye reports. Often there is just a description of what the doctor thinks the child can see.

By careful observations over a period of time, we can get a good idea of what your child sees. For example, does your child seem to recognize you visually? Can he choose his bottle from other bottles of similar shape or color? Does he recognize a familiar toy using only his eyes?

The causes of loss of visual acuity can vary. The child may be very near or far sighted and even glasses may not be enough to correct his vision to normal. For example, the child may have albinism resulting in a macula that never fully developed, so he does not see clearly enough to read to the 20/20 line. Glasses will not fix the problem. However, he may also have a refractive error which causes him to be near sighted as well. If you remember from our previous topic discussions, a refractive error means that his eyes are not able to bend light rays appropriately to have the rays focus clearly on the retina at the back of the eye. Glasses can fix that part of the vision loss. Without glasses, he may have 20/200 vision, but with the glasses, his vision may improve to 20/100.

Another cause of acuity loss may be something within the eye that blocks the light rays from reaching the back of the eye. This could be something like cataracts and corneal opacifications - a cloudy lens or cornea. Or else it could be that the retina, particularly the macula, and/or the optic nerve may be damaged or not fully developed. The bottom line is that the brain does not get a clear picture signal.

Surgery does not always fix visual acuity loss either. Sometimes it helps with cataracts and corneal opacifications. Usually, not much can be done about problems in the retina or optic nerve, except surgery for some kinds of retinal detachments or to relieve pressure caused by a tumor or fluid on the optic nerve. We cannot transplant an eye or optic nerve because of the billions of fibers that would have to be correctly reconnected.

In later topics, we will have a chance to explore more closely what your child sees and how well he sees. We will work on ways to help him understand and make sense out of the blurs and blobs in his world. We will find ways to help make it easier for him to see, such as making things larger, getting your child closer to objects, adding more color or contrast, and using appropriate lighting.

Common disorders which have associated visual acuity loss are: high refractive errors such as found with children with Down syndrome; cataracts; retinal detachment; ROP; glaucoma; Leber's amaurosis; underdeveloped eye as in microphthalmia; retina, macula, and/or optic nerve hypoplasia; optic nerve atrophy; albinism; and, aniridia. (See Appendix C on page 638 for descriptions of common ocular disorders with associate functional implications found in young children.)

LOSS OF VISUAL FIELD

A child with a visual field loss is limited in how large of an area he can see. Let me show you what I mean. [Have the parents look through a couple of field loss simulators, such as those representing tunnel vision or central field loss. Make sure one of the simulators is a mixed simulator which simulates both the child's field and acuity loss.] As you can see, there are varying degrees of field loss. Most of us can see an area of about 160° - 180° in front, above, below, and to the sides of the eyes while holding both our head and eyes still and looking forward. A child with a visual field of 20° or less in his best eye, which is like looking down a tunnel or the tube of a roll of toilet paper, is considered legally blind. The acuity in that eye may or may not be normal. More often than not, it is poor. As you experienced, even with good visual acuity, a severe visual field loss can make reading and just getting around quite difficult. Some children have "islands" of vision which might be like looking through swiss cheese. Other children have just the opposite with little "blind spots" scattered around their visual field. If a child has lost his central visual fields, or central vision, he may have problems with seeing color and fine detail. He will have to use his peripheral visual fields, or side vision, for getting around and seeing things.

It is not uncommon to see the word scotoma which means a blind spot or area in which a child does not see. The child has to learn to look around it. When a total loss of half of the visual field occurs, it is called a hemianopsia. For example, a child with a left hemianopsia may only see the right half of his high chair tray at one time and may not see the food on the left side of the tray.

It is common to see a child with a central field loss holding his head in a different position when he is looking at people or things. This allows the image of the person or thing to fall on the area of his retina that is giving him the best vision. This is one way in which the child has learned to compensate for not having a full visual field. Some children with nystagmus (jerky eye movements) may also use a different head posture when looking. This is because of where their "null" point is. This is usually a point in the periphery where they are better able to hold their eyes to decrease the jerky movement, thus giving them a slightly clearer image of what they are looking at.

It is very difficult for doctors to measure a young child's visual fields accurately. Sometimes, the doctor may only get a general idea as to where any field problems may be and where your child sees the best and the worst.

By carefully observing over time your child's behavior when he is looking, we can get a good idea as to where your child sees the best. For example, when he looks at you or a toy, does he have a tendency to look from one side? Does he bump into things on one side? Does he trip over things quite often? Does he look at you by dropping his chin and tilting his eyes? [If the child utilizes an unusual head and/or eye position when looking or using his vision, you and the parents can try to analyze what that means. Begin to talk about the behaviors that indicate where the child might see best. Remember, when the child also has a motor impairment, it may be more difficult to sort out how much of the head and/or eye positioning is due to his visual loss and how much is due to the motor impairment. Talk to the child's physical or occupational therapist to make sure that the head position is not a head or neck problem in need of strengthening.

Visual field losses can be caused by any eye problems that block the light rays from reaching the back of the eyes. These could be things like cataracts and corneal opacifications - a cloudy lens or cornea. More often, a field loss is the result of damage or abnormalities of the retina or optic nerve such as a detached retina, retinitis pigmentosa, or a brain tumor putting pressure on the optic nerve. A field loss does not always mean that the child sees nothing in a particular area. It can mean that vision may be more blurred in that area than in other areas. If there is damage somewhere along the optic nerve tract, doctors can sometimes estimate where it is by looking at how a child's visual fields are affected. (Use Diagram V-11, "Different Problems That Can be Found in the Optic Nerve Pathway With the Resulting Visual Field Loss", if it would help the parents better understand the child's field loss when damage to the visual pathway or visual cortex is involved. You may need to help orient the parents to this somewhat complex figure to aid in their understanding it.)

Usually, there is very little that can be done medically for a field loss unless the disorder happens to be operable, as in the case when a cataract is removed or part of a retina is reattached. Has your child's doctor discussed any type of treatment that he feels would help reduce the severity of your child's visual field loss?

In later topics, we will have a chance to find out more about your child's visual field loss. We will teach him some ways to compensate for his loss, such as using search patterns and scanning to piece his fragmented views of things into wholes.

[Common disorders that result or could result in field loss are Stargardt's disease (or any other type of macular degeneration), retinitis pigmentosa, retinopathy of prematurity, glaucoma, retina detachments, and tumors putting pressure on portions of the optic nerve tract. See Appendix C on page 638 for descriptions of specific ocular disorders and their associated functional problems.]

REDUCED CONTRAST SENSITIVITY

A child with reduced contrast sensitivity has difficulty telling the relative difference between the lightness and darkness of whatever he is looking at. Everything can appear washed out, like looking at a faded photograph. This is especially a problem for a child trying to tell things apart that are almost the same color.

Reduced contrast sensitivity can affect how a child perceives his world around him visually. It can affect his recognizing faces, his ability for locate things with his eyes, and even his posture.

Reduced contrast sensitivity can be the result of reduced visual acuities and visual fields, glare, or even problems in the functioning of the visual cortex at the back of the brain.

Some things can be done to enhance contrast sensitivity such as by using sunglasses/filters, changing the amount and/or type of lighting, or other modifications in the environment. (Such modifications will be covered later in Sections 2.)

[Virtually all disorders affect contrast sensitivity to one degree or another. Some primary eye care practices and low vision services can assess a child's contrast sensitivity and make specific recommendations on how to utilize or enhance the child's current contrast sensitivity.]

OCULOMOTOR PROBLEMS

A child with oculomotor problems - problems with the muscles of the eyes - has difficulty with coordinated movements of his eyes. He may not use his eyes together when looking at or following a moving person or thing. He may look with one eye and then the other. As he watches people or things come in close to him, one eye may turn in or out, or both eyes may turn in (cross) or out. The child may have trouble following fast moving things such as balls. He may lose track of them completely. He may have difficulty in reaching for things accurately.

In the case of oculomotor problems, the coordinated way the six muscles that move the eye together stops happening. There are several possible causes for this. The frontal lobe of the brain, which helps control the movements of the muscles that move the eyes, may be damaged. A nerve to one of the muscles may be damaged, thereby paralyzing the muscle. One muscle may be longer or shorter than normal so it may not pull far enough or too far. An eye problem may have decreased the visual acuity in only one eye so much that that eye is no longer able to work equally with the better eye.

Problems caused by the muscles that move the eye not working properly can be very complex and difficult to treat. Some problems are corrected or at least improved with glasses and/or medication, or even surgery. Others might be helped by patching the better eye in order to make the poorer or weaker eye learn to work and become stronger. The younger the child when treatment is provided to correct the imbalance, the better is his prognosis for developing improved vision. So, it is critical that muscle problems are identified during the infant and toddler years.

In some cases, such as a child with cerebral palsy who has had damage to the frontal lobe of the brain, there may be nothing that can be done. The problem is the brain itself. With children who have other motor impairments, it is often hard to determine how much of the problem is caused by the child's vision problems and how much by the child's motor problems. Again, it may be helpful to consult with the child's OT or PT on this problem.

Often a problem with the eyes not moving together causes the child to see double. The more severely affected eye starts to be used less and less. The information sent to the brain by that eye may start to be ignored by the brain (suppression) in order avoid the double vision. If this goes uncorrected, the child can become amblyopic - or functionally blind - in that eye.

Another oculomotor problem that is present in many children with vision problems is nystagmus. This means the child's eyes move in rhythmic jerks. This movement may be in a side to side pattern (horizontal), in a circular pattern (rotary), etc. This is not because the muscles that move the eyes are not working together. It is believed that the normal saccades (movements) of the eye as it fixates become exaggerated in low vision children to the degree that these movements can be observed. Nystagmus sometimes decreases as the child gets older. (If the parents want to know more about this, or it is present in the child, take more time to discuss it.)

[Common terms related to oculomotor problems are strabismus, exotropia, esotropia, alternating exotropia, hypotropia, hypertopia, phorias, and amblyopia. See Diagram V-12, "Normal Gazes" and Diagram V-13, "Heterotropia or Strabismus". See Appendix C on page 647 for descriptions of specific ocular disorders.]

PROCESSING PROBLEMS

A child who has had damage to his brain and also has a cortical visual impairment has a visual cortex that is having difficulty processing and making sense of the information sent to it by the eyes. Very often, the child has healthy, normal eyes and optic nerves.

Let me give you an idea of what this is like. (Show the parents Diagram V-14, "Vision is More Than 20/20 Eyesight". Ask them if they know what the picture is. Let them hold it in any position they would like. If they cannot figure it out after a few minutes, then point out the features and tell them what it is: a cow. Remind them that they have normal eyes and nerves, but their brain is not making sense of the picture.)

Very early in life, children with visual processing problems function as if they are blind. However, with time, stimulation, and neurological maturation, they often progress. This even happens after four or five years of age. In other words, a baby who appears to be blind, one year later may be looking, reaching, and following toys and faces with his eyes. The amount of progress varies from child to child. It will be less if the child has additional problems in the eye or optic nerve. In later topics, we will learn about ways to help children who have cortical vision problems make sense out of their world. However, there is very little that can be done for these children medically.

If an eye doctor suspects cortical visual loss and is unable to get any type of visual response from a child with low vision and multiple handicaps, he may recommend that the child be given a special electronic test called a VER (Visual Evoked Response). This test may let the doctor know for sure if a breakdown has happened in the child's visual cortex by showing whether or not the visual signals are reaching the visual cortex at the back of the brain. The MRI (magnetic resonance imagery) is another test that may be used to diagnose cortical visual impairment.

Although many children with multiple and severe impairments have cortical vision impairments, the term is often overused for something we know little about. The visual cortex can be damaged by severe head injuries, infection like meningitis, prolonged hydrocephalus, and/or difficult birth with associated oxygen deprivation. In addition, some children are born with underdeveloped or even absent brains. See Appendix C, page 642, for more information on CVI.

SAMPLE ACTIVITIES

1. Follow through with the activities in the Sample Discussion (e.g., using low vision

simulators, looking at and discussing the confusing picture of the cow, etc.).

2. Together do some brief observations related to determining the child's visual acuity and visual field (if and how he positions his head and eyes, if he has an oculomotor problem, etc.).

SAMPLE CHALLENGES

1. Read an article (in a pamphlet or section of a book) about your child's vision problem. See if you can find out more information about his vision problem at the library or from your child's eye doctor. You might also want to write to an organization, such as the one listed below, for more information about your child's vision problem

   The National Association for
   Parents of Visually Impaired
   2180 Linway Dr.
   Beloit, WI 53511
   (608) 362-1380

2. I will leave you with the simulator most like your child's vision loss. Use it off and on throughout the week as you do routine tasks about your home or work - but be careful!. You may even want to spend a whole day wearing it. Again, be careful, and make sure someone else is around in case you need help. We will talk about your experiences next week.

3. Make some informal observations this week of how your child functions with his eye problem.

REFERENCE AND READING LIST

1. Barraga, N. C. & Morris, J. E. (1982). Program to develop efficiency in visual functioning: Source book on low vision. Louisville, KY: American Printing House for the Blind.
2. Duffy, M. & Beliveau-Tobey, M. (1991). New independence!. Philadelphia, PA: Institute for the Visually Impaired/Pennsylvania College of Optometry.
3. Jose, R. T. (Ed) (1983). Understanding low vision. New York, NY: American Foundation for the Blind.
4. Lovie-Kitchin, J. E. & Bowman, K. J. (1985). Senile macular degeneration: Management and rehabilitation. Boston: Butterworth.
5. Harrell, L. & Akeson, N. (1987). Preschool vision stimulation. It's more than a flashlight developmental perspectives for visually and multihandicapped infants and preschoolers. American Foundation for the Blind, New York, NY.
6. Hanson, Mary. Beyond tracking: Enhancing vision development from birth to one year of age.
7. Zolot, M. (1980). Infant vision. Optometric Extension Program Foundation, Inc. Santa Ana, CA.
8. Erhardt, R. P. (1990). Developmental visual dysfunction. Models for assessment and management. Tucson, AZ: Communication Skill Builders.

Diagram V-9

THE EYE COMPARED TO A VIDEO SYSTEM

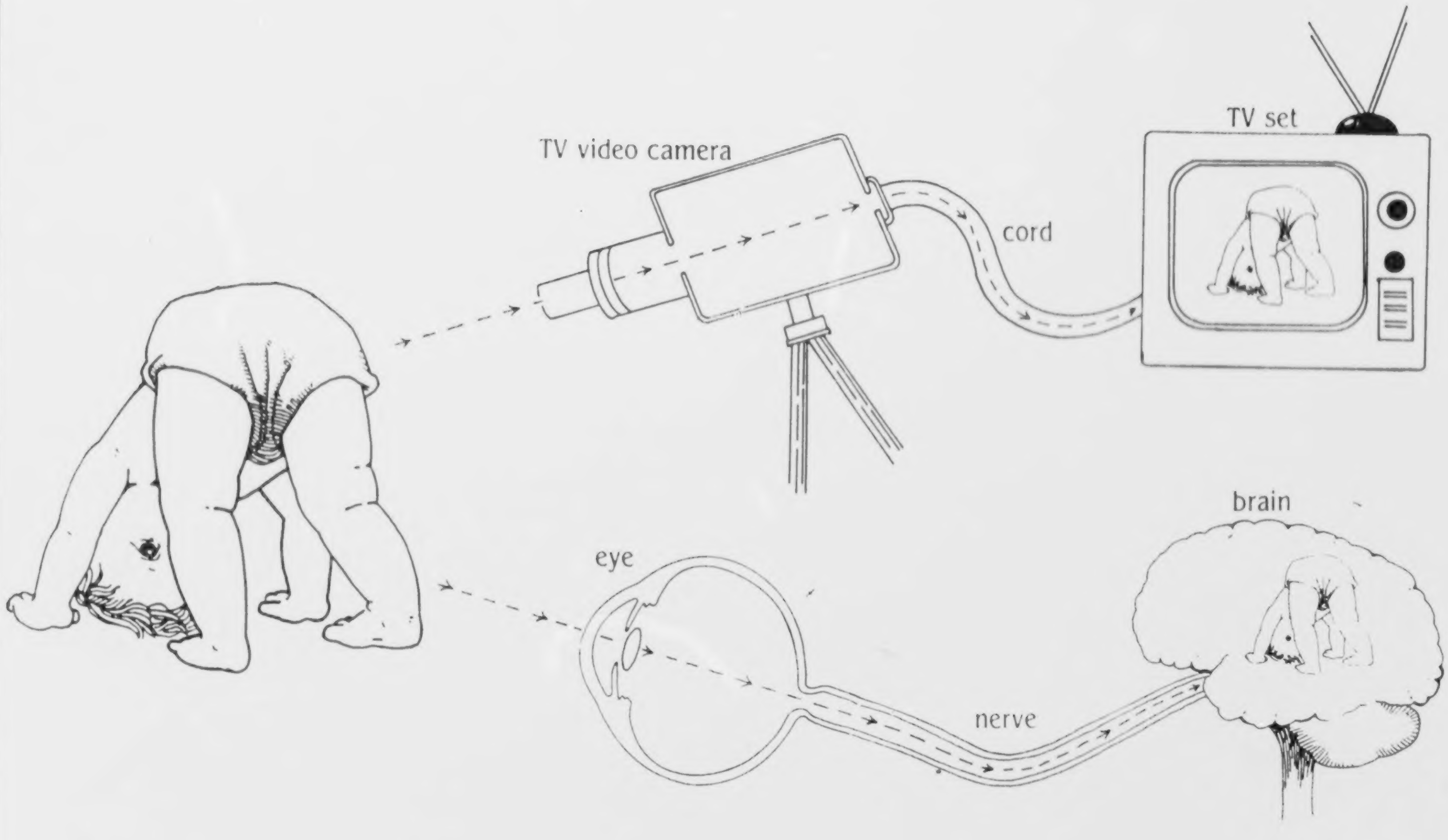
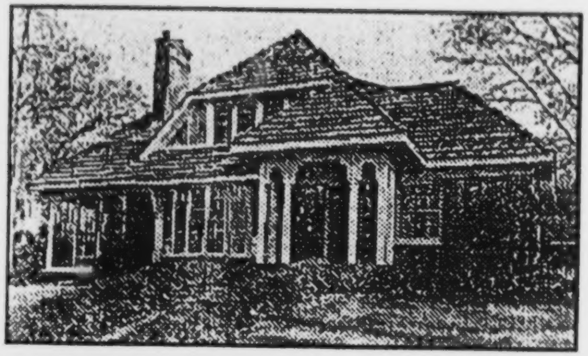

TV video camera
cord
TV set
eye
nerve
brain

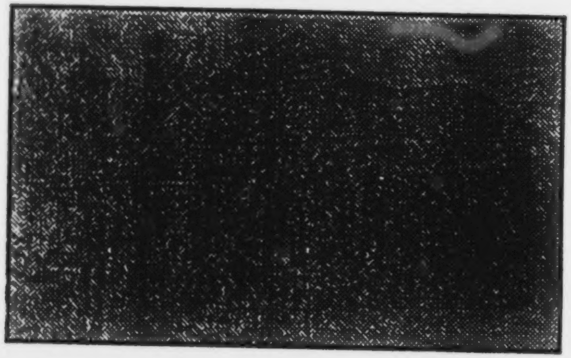
Diagram V-10

HOW VISUAL LOSSES APPEAR

LOSS OF VISUAL ACUITY



Normal visual acuity
lets us see sharp details
of this house both close up
and far away.



The loss of visual acuity
causes 'blurry' vision. The
child may be able to see the
shape of something, but not
the details.

A person has low vision if the acuity in his best eye with the best correction is between 20/50 and 20/200 (AFB).

A person is legally blind if visual acuity is 20/200 or worse in the better eye with the best correction possible.

In the U.S., One in 500 people are legally blind.

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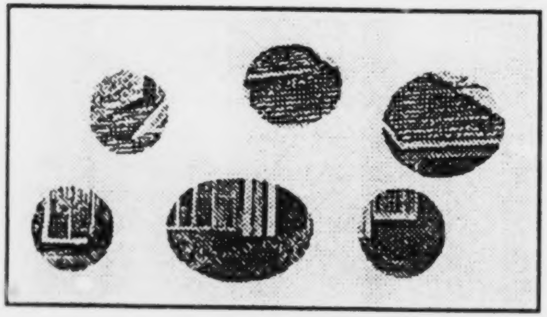
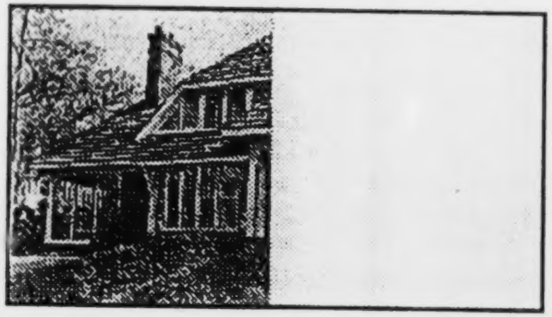
LOSS OF VISUAL FIELDS



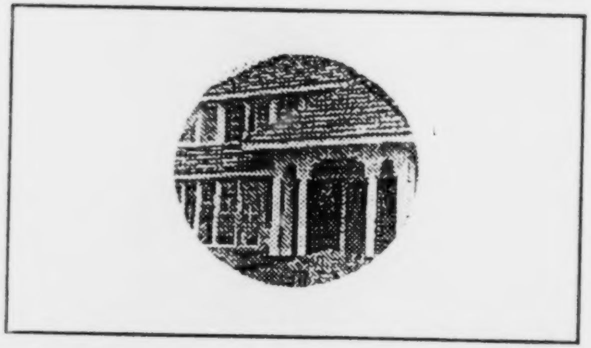
'ISLANDS' OF VISION: a child with this type of field loss only sees islolated parts of people or things when he is looking at them. Like with scattered blind spots, the child's functioning will be determined by how big, how many, and where the islands of vision are.



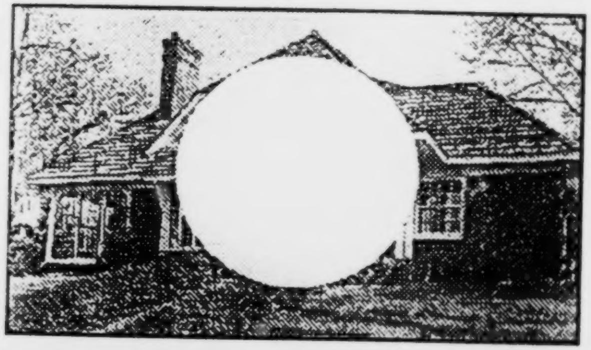
HEMIANOPSIA: A child with this type of field loss only sees half of the people or things when he is looking at them. This half of visual field could be left or right or top or bottom. The child may not notice or bump into people or things 'hidden' in the half of the visual field that has no vision.

A person is legally blind if their visual field is 20° or less in the better eye with the best correction possible.

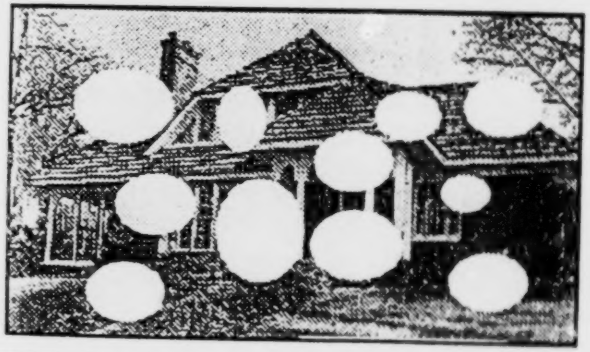
LOSS OF VISUAL FIELDS



LOSS OF PERIPHERAL (CENTRAL) VISION: A child with this type of field loss will be able to only see straight ahead and will not be able to see people or things at the sides without turning his eyes or head. This is sometimes called tunnel vision. It is like looking through an empty tube of toilet paper.

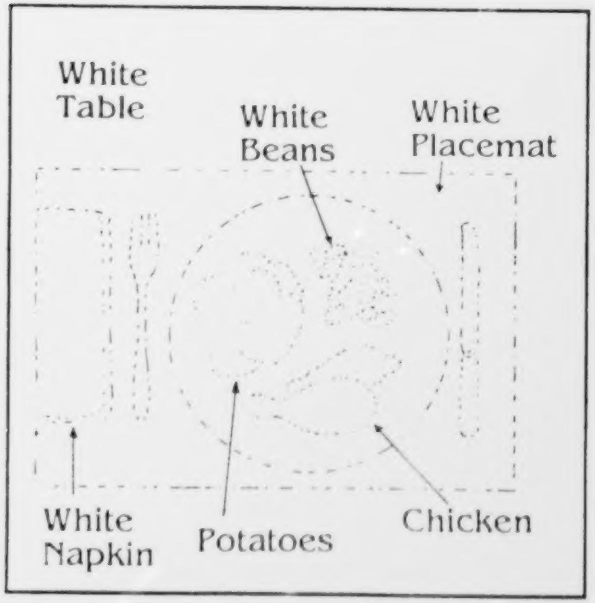


LOSS OF CENTRAL VISION: A child with this type of field loss will only be able to see a blind or grey spot straight ahead no matter which way he turns his eye. It is like looking at a picture with a spot in the middle.



SCATTERED BLIND SPOTS OR SCOTOMAS: A child with this type of field loss may loose 'parts' of people or things when he is looking at them. How big the blind spots are, where they are located, and how many there are, will affect how severe the child's visual functioning will be.

LOSS OF CONTRAST SENSITIVITY

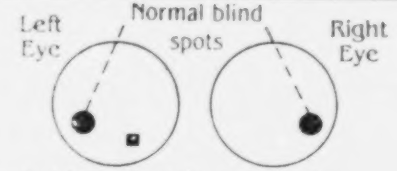

White Table
White Beans
White Placemat
White Napkin
Potatoes
Chicken

CONTRAST SENSITIVITY is our ability to tell the difference between the lightness and darkness of things we see. It can also be explained as being able to tell things apart that are almost the same color.

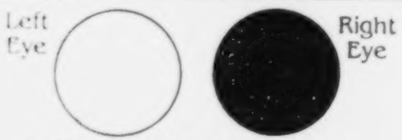
To a child with the loss of contrast sensitivity, everything can appear "washed out". It's like looking at a faded photograph.

Diagram V-11

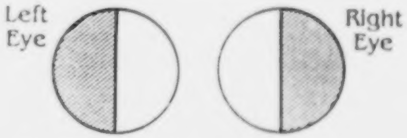
DIFFERENT PROBLEMS THAT CAN BE FOUND IN THE OPTIC NERVE PATHWAY WITH THE RESULTING VISUAL FIELD LOSS


Left Eye
Normal blind spots
Right Eye

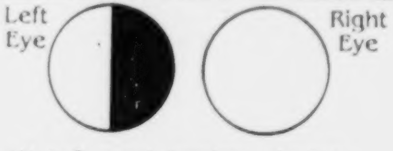
(1) Lesion in left superior temporal retina causes a corresponding field defect in the left inferior nasal visual field.


Left Eye
Right Eye

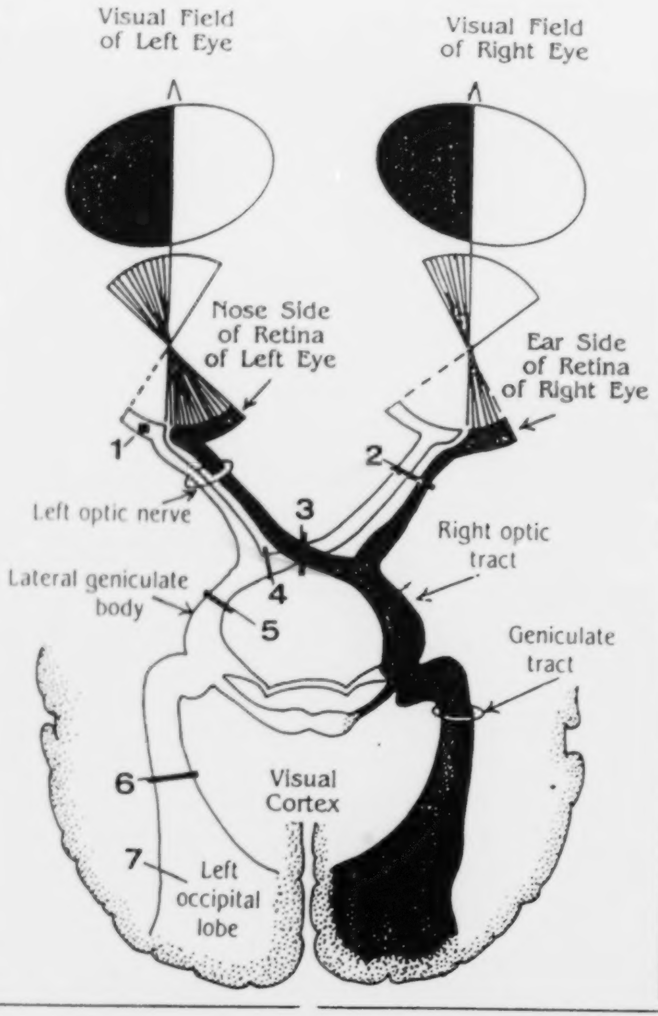
(2) Total blindness, right eye. Complete lesion of right optic nerve.

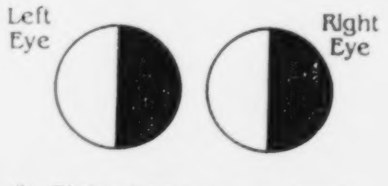

Left Eye
Right Eye

(3) Chiasmal lesion causes bitemporal hemianopsia.

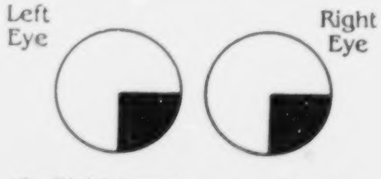

Left Eye
Right Eye

(4) Left nasal hemianopsia due to a lesion involving the outer aspect of one side of the chiasm (pressure on the optic nerve from aneurysm of left internal carotid artery).

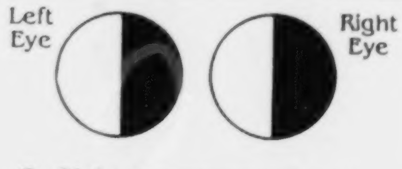

Visual Field of Left Eye
Visual Field of Right Eye
Nose Side of Retina of Left Eye
Ear Side of Retina of Right Eye
1
2
3
4
5
6
7
Left optic nerve
Right optic tract
Lateral geniculate body
Geniculate tract
Visual Cortex
Left occipital lobe


Left Eye
Right Eye

(5) Right homonymous hemianopsia due to a lesion of the left optic tract (least common site of hemianopsia).


Left Eye
Right Eye

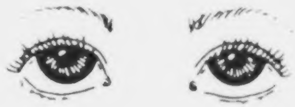
(6) Right homonymous interior quadrantanopsia due to involvement of optic radiations (upper left optic radiation in this case).


Left Eye
Right Eye

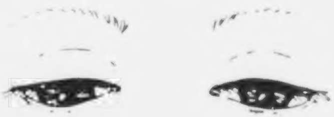
(7) Right homonymous hemianopsia due to a lesion of the left occipital lobe. The pupillary light reflex is not impaired.

Diagram V-12

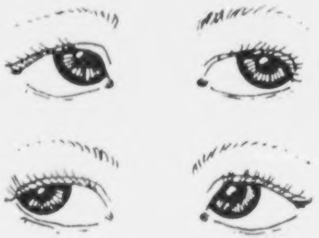
NORMAL GAZES



When you move your eyes straight up, each eye is being pulled by 2 muscles. One moves it up and in; the other moves it up and out. These are the superior rectus and inferior oblique muscles.

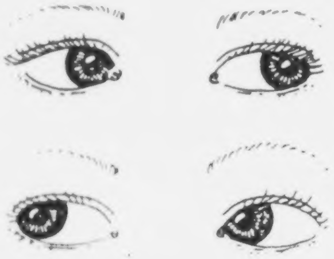


When you move your eyes straight down, the two muscles being used on each eye are the inferior rectus and superior oblique.

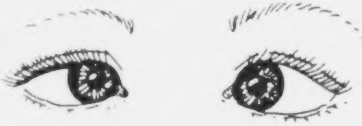


When you move your eyes up and to the left, the superior rectus and inferior oblique work together. On each eye, one muscle must exert a stronger pull than the other to achieve the turn to the left. In the left eye it is the inferior oblique; in the right eye, it is the superior rectus that pulls harder. The opposite would take place when looking up and to the right.

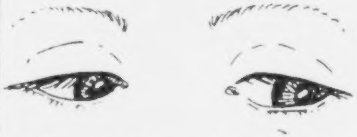
When you move your eyes to the side, just **one** muscle is exerting a pull on each eye. When looking to the left, the muscles exerting the pull are the external rectus in the left eye and internal rectus in the right eye.



When looking to the right, the internal rectus exerts the pull in the left eye and external rectus exerts the pull in the right eye.



When cross-eyed, the internal rectus in both eyes exerts the pull on each eye.

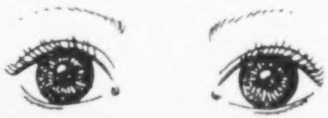


When looking down and left, the inferior rectus and **superior oblique** exert the pull in the left eye; the **inferior rectus** and superior oblique exert the pull in the right eye (underlined muscle exerts greater pull).

Diagram V-13

HETEROTROPIA OR STRABISMUS

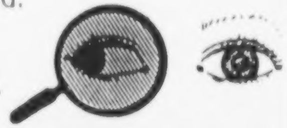
Phorias



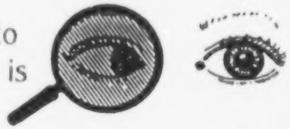
fusion keeps
eyes straight

Exophoria A tendency for one or both eyes to turn out when fusion is interrupted.

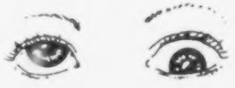
Cover right eye and
it wanders to the right.



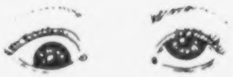
Esophoria
A tendency for one or both eyes to turn in towards nose when fusion is interrupted.



Right hyperphoria
Right eye tends to turn upwards; left turns downwards.



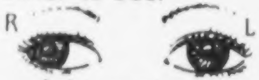
Left hyperphoria
Left eye tends to turn upwards; right turns downwards.



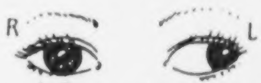
These can be overcome by natural desire for fusion. They can cause eye strain and headaches or blurred vision. Are not as serious as conditions in the right column nor are they as obvious. Correct with glasses, medication, patching, and/or surgery.

Tropias

Exotropia
Turning outwards of one or both eyes, causing person to see double or suppress vision in one eye and use the other to see.



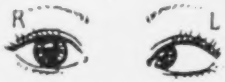
right exotropia



left exotropia

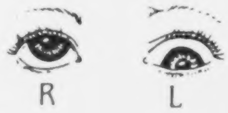
Esotropia
Turning inwards of one or both eyes causing the above.

right esotropia

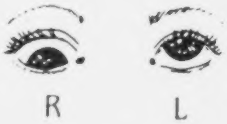


left esotropia

Right Hypertropia
Right eye turns upwards and left turns downwards causing the above.



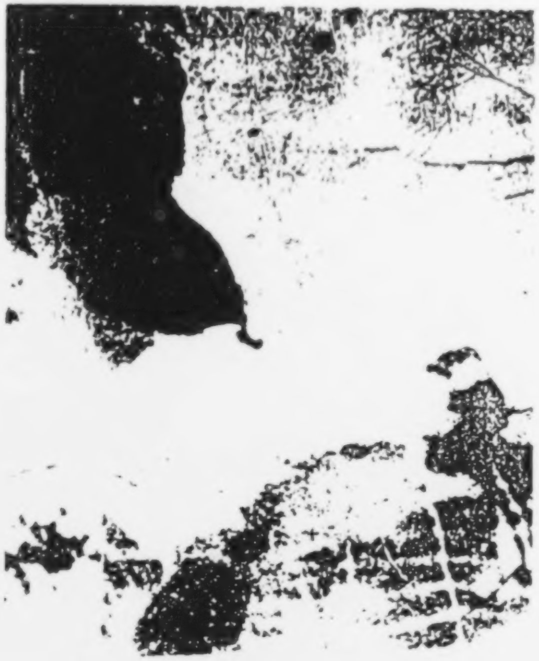
Left Hypertropia
Left eye turns upwards and right eye turns downwards causing the above.



These conditions are worse in degree than the ones on the left and are obvious when looking at child's eyes. May be corrected with patching, glasses, medication, and/or surgery.

Diagram V-14

VISION IS MORE THAN 20/20 EYESIGHT



WHAT IS IT?
This fascinating picture is not an illusion.
It is an actual photograph of a familiar subject.

CAN YOU SEE IT ???

You may not immediately see the subject of the photograph on the reverse side because the seemingly meaningless blobs of light and dark require VISUAL interpretation. When you "see" the subject, you have VISION; before that you had only eyesight. Vision is the ability to get MEANING from eyesight.

Many people have clear "eyesight," but are slow readers, or have difficulty to get MEANING through the visual pathway. Such persons are handicapped in business, social and school life. Many also suffer visual discomfort or fatigue while reading or doing other close work.

The correction of these problems and the care of this complex physical and mental process called VISION require a highly specialized professional service - a service provided by the modern optometrist concerned with seeing as applied to clarity of eyesight AND the ability to get MEANING through vision.

Published in the interest of better vision by the Optometric Extension Program Foundation, Inc. (Nonprofit), Duncan, Oklahoma, an international organization dedicated to postgraduate education and research in vision.

ACTIVITY:

"WHATZIT?"

BEST COPY AVAILABLE

Activity:

"Whatzit?"

There are 20 numbered paper bags on the side table. Each bag contains a familiar object.

Without looking inside, reach into a paper bag and feel the object. Are you able to identify it by touch alone? Look at the number on the outside of the bag and write what you think that object is on the appropriate line below. Try to do this with all 20 bags - or as many as time allows.

1. ______________________________
2. ______________________________
3. ______________________________
4. ______________________________
5. ______________________________
6. ______________________________
7. ______________________________
8. ______________________________
9. ______________________________
10. ______________________________
11. ______________________________
12. ______________________________
13. ______________________________
14. ______________________________
15. ______________________________
16. ______________________________
17. ______________________________
18. ______________________________
19. ______________________________
20. ______________________________

Possible Developmental Delays of a Child with Severe Vision Impairment

Possible Developmental Delays of a Child with a Severe Vision Impairment

(The following information is adapted from the
INSITE TRAINER'S MANUAL - SKI*HI Institute)

Social:

The child's bonding with parent(s) is harder to establish and more easily interrupted. There are several reasons for this. The smile response is established late and may not be as frequent; it is harder to evoke. Since the child's vision is affected, the child does not respond to a parent's approach as would a child with normal vision: thrashing, making noises, etc. Rather the child becomes still in order to hear the parent better. The parent may view this as rejection by the child. There may be minimal or no eye contact by the child. Parents must learn to be observant and watch the baby's hands for signals that the child wants to interact with the parents. Since visual input is missing, the baby's main interest is focused on her own body; her parents may interpret this to mean that the baby wants to be left alone. The baby needs a lot more touching, however if the parent feels that the child is not bonding with them, they may feel reluctant to touch or hold the child.

Parents are often overprotective; combining this with the child's lack of vision for incidental learning by observation, social norms often need to be taught. This child may have difficulty in developing a concept of self as separate from other. Because of delays in concept development (and, often, from overprotection by the parents) the child is often much less independent. Due to the lack of vision input and incidental learning, the child may lack awareness of social expectations.

Because the child does not have the benefit of seeing the many ways we show our feelings through body language (facial and body), the child does not appear expressive.

Play:

Interaction skills with other children in play may be a problem. The child may demonstrate less variety in play. Make believe play is delayed (may appear as late as four to five years of age) and once the child has entered this stage of play, the child may remain in fantasy play longer. The child is often less interested in miniatures (such as doll houses, toy cars, etc). As a toddler, the child may sit and stay rather than explore her environment; the child may need to be motivated to find out all the interesting things in her environment with which she can play.

Cognition:

Object permanence is slower in appearing. The child may need help in learning how to problem solve. The child has a difficult time transforming experiences of touch and sound into mental images. The child may experience delays in whole-to-part concept development. The child may be less flexible, more rigid in thinking. The child may have trouble with problem solving and predicting outcomes. The child continues an egocentric view of the world longer than normal. Concept of time and space is not normal. Accurate and meaningful experience are critical for the child to develop good cognition. The child may need more help with organizing concepts.

Communication and Language:

The baby may babble a lot the first year, but in a subdued way. The baby may quiet quickly when people are present in order to hear what's happening around her. In some cases, the child has problems with the function and purpose of language; the child may exhibit verbalism and echolalia (this is a form of stimulation). Many words can be meaningless to the child because she can't see clearly the picture of object connected with the sounds. The child may have problems with pronouns (the child may not use the word "I" but may refer to herself by her name) and abstract words. The child's development of speech and basic syntax may be normal by the age of four to five years, however, the child may be overly verbal.

Self Care:

The child may need longer time to learn specific skills; the child may need more hand-over-hand/co-active help form parents and others in the early learning stage of an activity. Parent over protection may get in the way.

Child may be messy self-feeders - parents may be tempted to prolong feeding the child delaying independence. Child may initially be resistant to various food textures. Child may not chew properly and may only want to eat pureed food (this may be the result of not seeing chewing modeled). The child may delay desire to self spoon feed since she does not see others do it and, therefore, doesn't understand that this is the social, "grown up" thing to do.

For dressing, the child may not understand colors and patterns. The child may not see front/back or inside-out so these concepts may be delayed in being established.

May mix up day and night sleeping patterns.

Gross Motor:

Child may have delayed head control and balance due to lack of a visual reference, therefore, other mobility skills such as getting into sitting, raising upper torso, crawling, and walking are quite delayed. A child with normal vision is motivated to raise her head off the floor in order to see her world, this motivation may not be there for the child with a vision impairment; furthermore keeping her chin on the floor may provide that child with additional sensory input. Sitting - first supported and unsupported - matches that of a child with no vision loss since the child with the vision impairment does not need to move - getting into and out of the sitting position, may be a problem. Child may "cruise" along objects for a longer period of time before starting to walk. Child may keep a wide base in her stance. Walking tends to be delayed until ages 18 - 19 months. Jumping, skipping, and running are hard for the child to learn and perform.

Fine Motor:

Child has to be taught to use her hands. While a 3 - 4 month old child with full vision is fascinated with watching her hands engage in the midline, the child with a severe vision loss brings her hands together only accidentally and not in a purposeful way. Reaching for sound is delayed 9 - 12 months. Child may be tactually defensive. The child may lack the vision to adequately monitor reach, grasps, and manipulation, therefore, tasks take longer until learned. Child may need hand-over-hand/co-active assistance and sound to help in the learning process. Many visually orientated tasks are not exciting to the child so many of the fine motor skills generally used in these tasks are therefore not re-enforced.

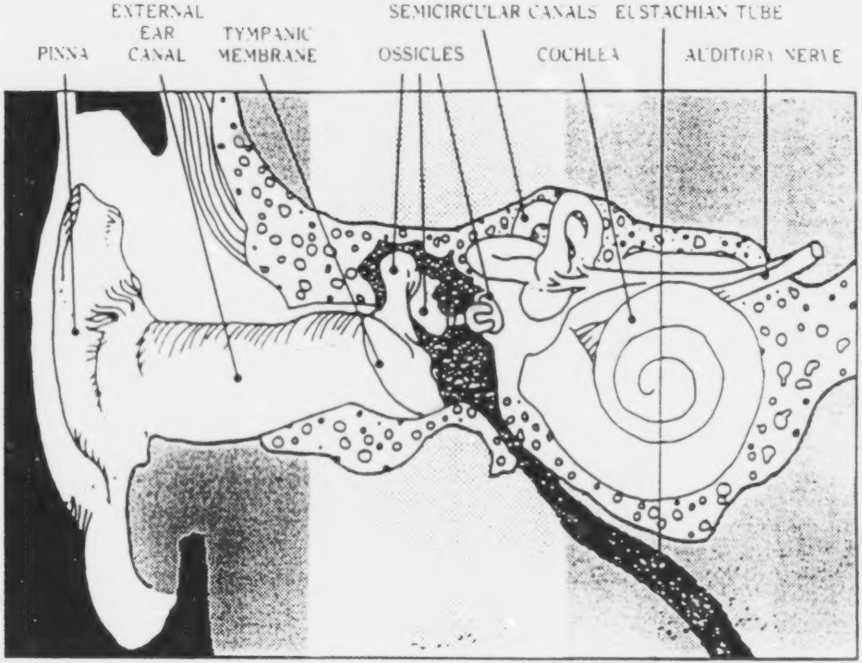
Other Behaviors:

The child may develop other behaviors ("blindisms"): eye poking; head shaking; rocking; reciting jingles and echolalia, etc.

How We Hear

RESOURCES AND READINGS

How We Hear


PINNA
EXTERNAL EAR CANAL
TYMPANIC MEMBRANE
OSSICLES
SEMICIRCULAR CANALS
COCHLEA
EUSTACHIAN TUBE
AUDITORY NERVE

OUTER EAR **MIDDLE EAR** **INNER EAR**

Sound enters the external ear canal and makes the tympanic membrane (eardrum) vibrate. The vibrations are transmitted to the cochlea through a series of three small bones, the ossicles. The vibrations set up in the fluid contained in the cochlea result in stimulation of the nerve endings in the cochlea and transmission of impulses to the brain through the auditory nerve.

The eustachian tube connects the middle ear and the throat, allowing equalization of air pressure on both sides of the eardrum. The semicircular canals play no role in hearing, but help a person maintain his balance.

THE INSITE MODEL

Home Intervention for Infant, Toddler, and Preschool Aged Multihandicapped Sensory Impaired Children

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TOPIC 1: SOUND; CONTACT WITH THE WORLD

PARENT GOALS

1. Parents will describe four reasons why sound is so important:

    A. communication, language;
    B. physical sensory development;
    C. psychological sensory development; and
    D. warning.

2. Parents will define:

    A. frequency: pitch of a sound;
    B. Hertz (Hz): frequency or pitch; and
    C. decibel (dB): loudness or intensity of a sound.

MATERIALS

- Figure H-1, "Amounts Of Hearing Loss"

- rubber band

- pencil

- pitch pipe, piano, or other musical instrument (can use voice to show different pitches)

INSTRUCTIONS TO PARENT ADVISOR

Discuss with parents the need for them to understand why sound is important. This information and the understanding of several professional terms will make it easier for them to deal with their child's hearing aids as well as other professionals they will come in contact with.

SAMPLE DISCUSSION

Importance Of Sound

Suppose you were very young like your child and did not know any words and suppose there was no sound to hear these words. Let's pretend there is no sound. I will not use my voice. See how much you can understand. [Drop voice and say a few words or sentences in a foreign language or use nonsense words.]

What did you understand? [Response: Nothing.] You see, when a child does not know a language (the words), it is very hard to understand what is being said, but it is even more difficult if there is no sound. So sound is important to help your child learn to communicate. We all learn language by hearing it during critical periods of readiness. It appears that the development of speech and language is based upon innate biologically programmed factors (Lenneberg, 1967). Thus, the earlier the child's hearing is helped by amplification, the better for the child's speech and language development.

Sound is important to learn to communicate, but it is also very important for other reasons:

1. Sound stimulates the development of your child's sense of hearing. Without sound, sensory deprivation (in this case, sound deprivation) results. The hearing system may deteriorate by prolonged lack of sound (sound deprivation) in early life.

2. The absence of sound can also affect psychological aspects of development. Sound allows your infant contact with the world so he can begin to trust the people and things in his environment. Sounds make your child feel part of the world. If the hearing aids only help your child come into contact with his world, it will be enough help. The expense and effort of putting on the hearing aids will be worth it.

3. Sound provides warning and helps your child to know how to act. If something falls behind him, he will know where to look. If a car honks, he can get out of the way. If mother shouts, he can come to her (or go the other way!). The hearing aid will help bring sound to your child.

What Is Sound?

Sound is something vibrating; i.e., something moving back and forth. As it moves forward, it pushes on air molecules and the molecules squeeze together. As it moves back, the molecules spread out.

When a plucked rubber band (or string on a musical instrument) moves back and forth one time, [demonstrate by moving finger back and forth], that is one cycle. If it moves back and forth ten times it would be ten cycles. If it moves back and forth 250 times in one second [try to demonstrate], that would be 250 cycles per second (refer to Figure H-1 and show 250 on audiogram). This would be middle C [play on piano or use pitch pipe or other instrument]. Another name for cycles per second is Hertz (Hz). If the source vibrates 250 times in one second that would be 250 Hz (middle C). How fast the sound source vibrates determines how high or low the sound will be. If it moves very slowly, 125 times in one second, a low sound (octave below middle C) would be heard. If it moves very rapidly (500 times in one second), a higher sound (one octave above middle C) would be heard. How high or low a sound is, is called pitch or frequency. A particular pitch or frequency is called a pure tone. A sound can be high or low and it can also be loud or soft.

Decibel (dB) is the term utilized for how loud a sound is. If a sound is very soft, it would be about 10 dB. Normal voice would be about 60 dB. If a truck passed by, that would be about 110 dB. Decibel is simply a measurement of loudness (like an inch is a measurement of length and a pound is a measurement of weight). This example audiogram [point to Figure H-1] shows what dB range is usually referred to as normal hearing, mild hearing loss, etc. Different audiologists may divide up the amount of hearing loss slightly differently; however, this is usually how it is done.

SAMPLE ACTIVITIES

none

SAMPLE CHALLENGES

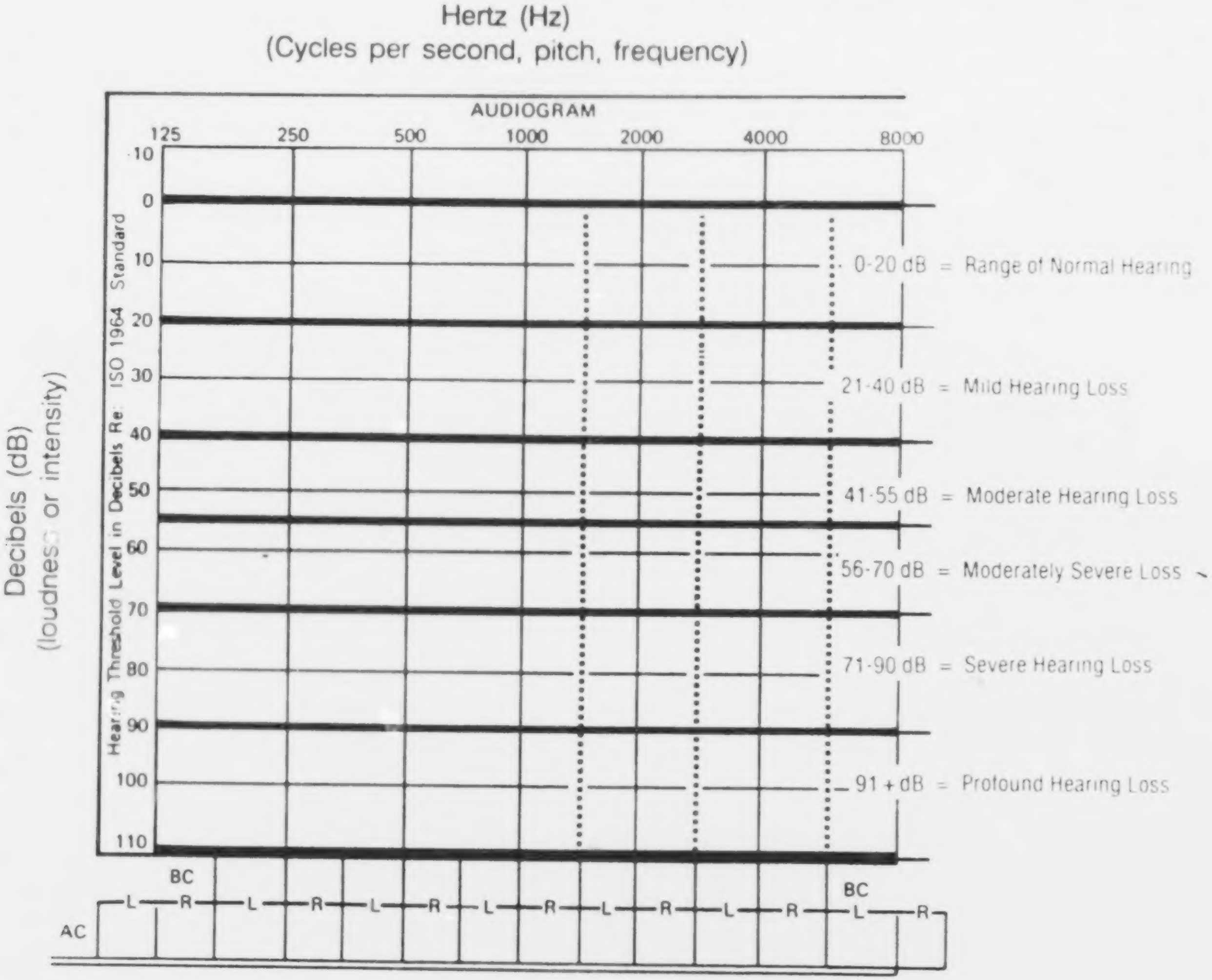
none

REFERENCE AND READING LIST

1. Lenneberg, E. H. (1967). *Biological foundations of language*. New York: John Wiley and Son.

Figure H-1

Amounts of Hearing Loss



TOPIC 2: PERCEPTION OF SPEECH; MINIMIZING BACKGROUND NOISE

PARENT GOALS

1. Parents will be aware how the perception of speech is affected by:

   A. the pitch of the speaker's voice;
   B. the loudness of the speaker's voice;
   C. the distance of the speaker's voice from the listener; and
   D. the presence of background noise.

2. Parents will establish four conditions for the best home listening environment:

   A. use a normal, conversational tone of voice;
   B. speak normally loud;
   C. be as close to the child as possible; and
   D. minimize background noise while speaking to the child.

MATERIALS

•Figure H-2, "Comparison Of The Frequency And Intensity Of Various Environmental And Speech Sounds"

•"A Sound Approach" (slide/tape presentation available through HOPE Inc., 1780 North Research Park Way, Suite 110, Logan, UT 84321)

•tape recorder

•slide projector

INSTRUCTIONS TO PARENT ADVISOR

For parents of less severely handicapped children with mild-moderate hearing losses, a discussion is available in the Middle Ear Program (SKI*HI Outreach Monograph Series) on the perception of speech relative to word meanings, functional relations of words (grammar), and prosody. This monograph can be obtained from HOPE Inc., 1780 North Research Park Way, Suite 110, Logan, UT 84321.

If available, show the slide/tape presentation, "A Sound Approach," and discuss its implications.

SAMPLE DISCUSSION

The perception of speech is the ability to be aware of, or notice, speech. People with normal hearing can hear the frequency range between 20 and 20,000 cycles per second (Hz) [point out range from far below to way above the 125 to 8,000 Hz range shown on Figure H-2]. It is known that normal hearing infants can hear the differences among many speech sounds almost from birth.

Infants are cued to their parents' speech by its distinctive pitch (the "musical" sound of speech). Men's vocal pitches tend to be in lower frequency regions (100-150 Hz) than women's (200-225 Hz). A child's speech is even higher in pitch than that of a woman's. The normal way you vary your pitch patterns while talking to your child helps him to perceive (be aware of) your voice.

The loudness of your speech varies very quickly within the range of about 30-60 dB [point out on Figure H-2]. For example, if you say the sound [sh], it may be approximately 20 dB louder than if you said the sound [th] as in the word "thing." Therefore, when you speak softly or when you are more than about two feet away from your child, he may not be able to hear the softer sounds ([f], [th], [s], [p]) of your speech.

Also, your child's listening environment often includes noise from television, other people talking, fans, air conditioners, appliances, etc. [show and discuss Figure H-2]. Often this background noise, which is almost as loud or even louder than your speech, masks out a significant amount of what you are saying to your child.

Distracting and competing noises make it difficult to hear conversations clearly. All surrounding noises, as well as speech sounds, are equally amplified with a hearing aid; thus, important communication and speech signals may be lost in background noise. When it is impossible to eliminate background noises completely, speaking close to the child makes the speech signal stronger and clearer.

Thus, when you are talking to your child, you should try to do the following:

1. Use a normal conversational tone of voice (pitch patterns).
2. Be sure to speak normally loud (not too softly).
3. Be as close as possible to your child when you are speaking to him, the closer the better.
4. Keep background noises at a minimum when communicating with your child.

SAMPLE ACTIVITIES

none

SAMPLE CHALLENGES

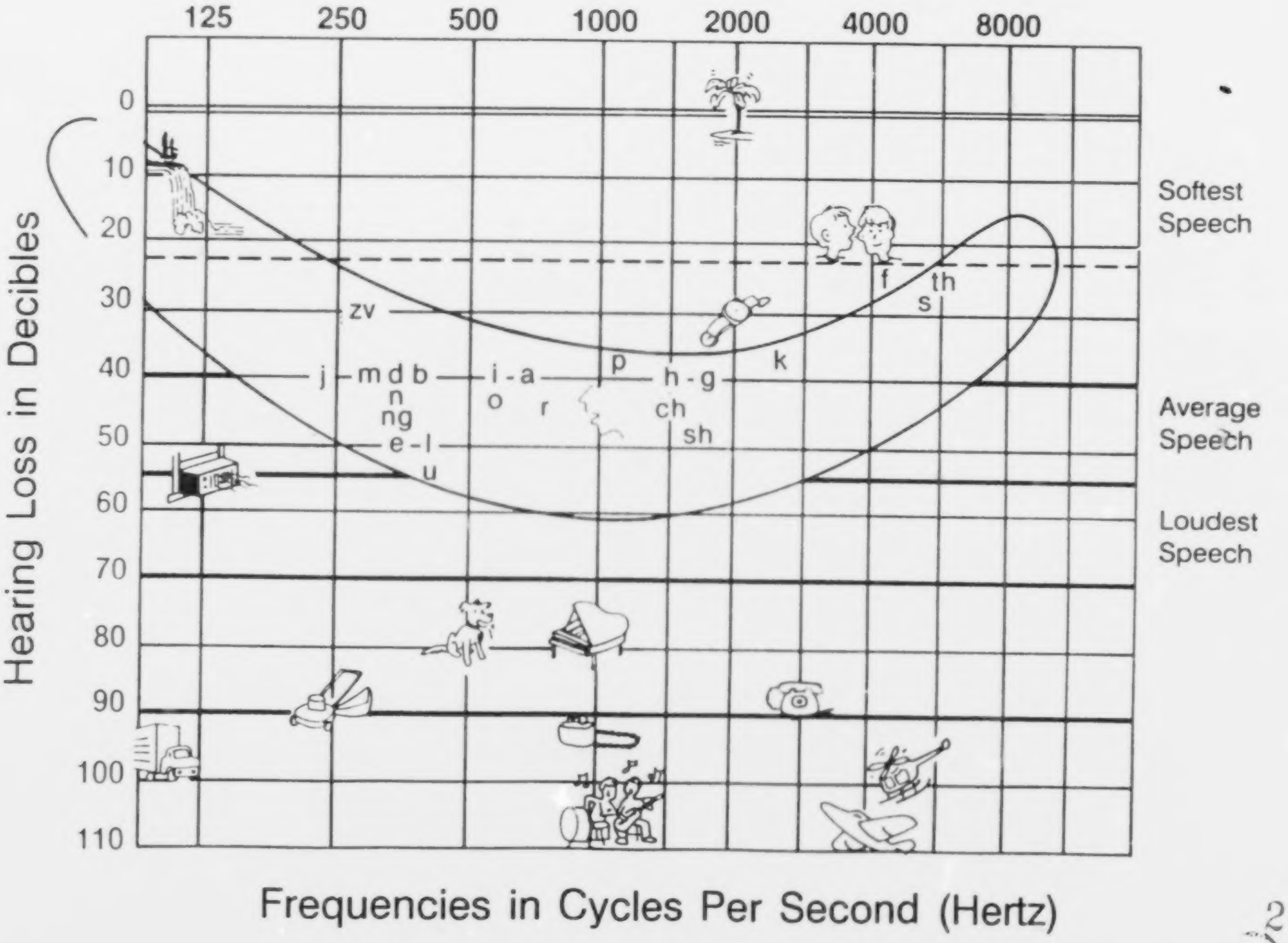
1. Make a list of background noises occurring during the home visit, during a normal day, in the car, at the store, etc.
2. Work to reduce distracting noises; discuss examples at next home visit.
3. Listen to competing background noises with your child's hearing aid on to determine the distraction effects of such noises.
4. Blindfold yourself and listen to distracting sounds. Discuss how to eliminate them.

REFERENCE AND READING LIST

1. Boothroyd, A. (1984). Getting the most out of hearing, the audiological and auditory management of hearing impaired children. *Audiology, 9*(2), 15.
2. Skinner, M. W. (1978). The hearing of speech during language acquisition. *Otolaryngologic Clinic of North America, 11*, 631-650.

Figure H-2

Comparison of the Frequency and Intensity of Various Environmental and Speech Sounds



TOPIC 3: OTOLOGICAL CARE; ANATOMY OF THE EAR; CAUSES AND TYPES OF HEARING LOSSES

PARENT GOALS

1. Parents will be aware of the various medical personnel available to their child and be able to state the need for continued medical care.

    A. Otolaryngologists or otologists give medical clearance for wearable amplification.

    B. Continued, periodic medical follow-up is necessary:
        1. to detect and treat middle ear infections;
        2. to detect progressive hearing loss; and
        3. to evaluate a balance problem.

2. Parents will be aware of the five parts of the hearing system and what is in each part.

    A. Outer Ear
        1. Auricle/pinna
        2. Ear canal

    B. Middle Ear
        1. Eardrum
        2. Bones: malleus, incus and stapes
        3. Oval window
        4. Eustachian tube

    C. Inner Ear
        1. Semicircular canals
        2. Cochlea
        3. Auditory nerve

    D. Brainstem
        1. Auditory nerve

    E. Brain
        1. Auditory cortex

3. Parents will be aware how sound travels from the sound source, through the ear and to the brain.

    A. Sound pushes eardrum.

    B. Eardrum pushes three bones.

    C. Last bone pushes on oval window.

    D. Oval window moves fluid in cochlea.

E. Moving fluid in cochlea stimulates the nerves in patterns.

F. Patterns travel up the brainstem.

4. Parents will be aware what can go wrong in each of the five parts of the hearing system and state what has gone wrong with their child's hearing system.

A. Outer Ear
   1. Wax plug in canal
   2. Canal and/or pinna not formed correctly or missing

B. Middle Ear
   1. Three bones broken
   2. Middle ear infections
   3. Hole (perforation) in eardrum

C. Inner Ear
   1. Nerve cells in cochlea damaged or missing
   2. Possible damage to balance mechanism

D. Brainstem
   1. Auditory nerves in brainstem damaged or failed to develop
   2. Auditory nerve tumors

E. Brain
   1. Brain cells damaged or missing
   2. Brain failed to develop

F. Area(s) damaged for this particular child

5. Parents will explain cause of their child's loss, if known.

MATERIALS

•Figure H-3, "Professionals Involved With The Hearing Impaired"

•Figure H-4, "Anatomy Of The Hearing Mechanism"

•Figure H-5, "The Cochlea"

•Figure H-6, "Anatomy Of The Brain"

•"Anatomy Of Hearing Loss" (slide/tape show available from HOPE Inc., 1780 North Research Park Way, Suite 110, Logan, UT 84321; use as review after the discussion)

•tape recorder

•slide projector

INSTRUCTIONS TO PARENT ADVISOR

Remember to utilize only the goal(s) from this lesson that the family has requested or that you select based on your awareness of the child's specific cause and type of hearing loss.

SAMPLE DISCUSSION

Medical Personnel Available And Periodic Follow-Up

The first step in obtaining hearing aids is medical clearance. [Show the parents Figure H-3, "Professionals Involved With The Hearing Impaired" and leave a copy with them.] This clearance can be provided by an otologist (ear specialist) or an otolaryngologist (ear, nose, and throat specialist) or a family doctor if a specialist is not available. Medical clearance is needed for hearing aid use because hearing aids may not be recommended if the hearing loss can either be medically or surgically improved in the immediate future.

Equally as important as initial medical clearance is the need for continued medical follow-up, especially of infants and young children who have frequent colds, allergies, influenza, other viruses, and bacterial infections of the throat that can cause associated middle ear problems. Many infants do not let their parents know when they have a middle ear infection; for example, by rubbing or tugging at their ears. Therefore, periodic checking is essential to determine if a middle ear infection is present when an upper respiratory infection (cold) is present. Even children with permanent hearing loss have middle ear infections which can temporarily cause a significantly greater loss of hearing.

Also, in a few infants, sensorineural hearing loss is progressive and this needs to be checked by periodic audiological testing. It is essential for hearing impaired infants and young children who experience dizziness or other balance problems to receive otologic care as soon as possible.

Anatomy And What Can Go Wrong
With The Five Parts Of The Hearing System

There are five parts of the hearing system [show parents Figure H-4]: (1) outer ear; (2) middle ear; (3) inner ear; (4) brainstem; and (5) brain.

The first area, the outer ear, has the ear flap (auricle or pinna) and the ear canal. Wax in the ear canal can build up and become compacted behind an earmold. Every child should be checked regularly for ear wax because it can cause temporary hearing loss and increase feedback (sound coming back out the ear) during hearing aid use.

The second area, the middle ear, contains the eardrum. The eardrum is connected to three tiny bones (malleus, incus, and stapes). The last bone (the stapes) is connected to the oval window. The eustachian tube is a small tube which goes from the top of the throat to the middle ear. It has two purposes. The first function of the eustachian tube is to let air into the middle ear and thus make the air pressure in the middle ear the same as the pressure outside the ear. For example, while driving up a mountain or flying in a plane, the ear may begin to feel plugged. The air outside is very "thin" but the air inside the ear is not. This heavy air inside the ear pushes out on the eardrums and causes a "plugged" feeling. Yawning will cause the "thin" air from the outside to rush into the mouth, up the eustachian tube and into the middle ear. This feels like a "pop." Now the air pressure is the same on the inside and outside of the middle ear or eardrum and the plugged feeling is gone. Letting air into the middle ear is also very important because having air in the middle ear helps to keep it from collecting too much fluid.

The second purpose of the eustachian tube is to drain fluid from the middle ear space. If there is fluid in the middle ear, it will run out of the ear and down the eustachian tube to the throat. Again, since young children have more colds, infections, and allergies, it is important to make sure there is no infection in the middle ear.

The third part of the hearing system is the inner ear. It has in it: (1) the semicircular canals which help with balance; (2) the cochlea which looks like a snail; and (3) the auditory nerve which goes to the fourth area, the brainstem. The brainstem carries sound to the fifth area, the brain.

How Sound Travels From The Sound Source Through The Ear And To The Brain

Something must vibrate for sound to occur. When something vibrates, air molecules are pushed together. The first molecule pushes the second molecule which pushes the third and so on until the molecules push in on the eardrum. The eardrum vibrates or moves back and forth at the same speed (or cycles per second) as the source. When the eardrum moves back and forth, it moves the three little bones, the malleus, incus, and stapes, back and forth [refer to Figure H-4]. The cochlea is filled with a fluid and has thousands of tiny nerve cells in it. As the last tiny bone (stapes) moves back and forth, it pushes on the oval window, which pushes the fluid in the cochlea back and forth [refer to Figure H-5]. As the fluid moves back and forth, the nerves are activated (stimulated) in a certain pattern. The nerves join together into one large nerve in the brainstem that carries the pattern to the brain.

As this pattern is traveling through the brainstem to the brain, it passes through several centers, apparently designed to perform a particular function. Some reflexes (for example, startle responses to loud sounds) and hypersensitive responses to sound are established at the brainstem level. The brainstem likely has other functions that at present are unknown or poorly understood.

The area of the brain where sound is analyzed is called the auditory cortex [show Figure H-6]. Although a great deal about how the brain functions is understood, scientists are still uncertain about the specific functions of the brain that underlie many of the problems observed in children with hearing loss.

What Can Go Wrong In Each Of The Five Parts Of The Hearing System?

When someone is hearing impaired, there is a problem with sound going through the ear to the brain. If there is a problem in the **outer ear** (wax block in the canal or the pinna and/or the canal fails to develop), sound cannot travel successfully through it.

Sound cannot travel through the **middle ear** if there are problems such as:

1. one or more of the three tiny bones are broken;
2. there is fluid or infection in the middle ear;
3. there is a hole (perforation) in the eardrum;
4. the middle ear is congenitally malformed (Pert's syndrome, Treacher Collins, Pierre Robin, osteogenesis imperfecta, etc.); associated disorders are often present.

If there is a problem in the outer or middle ear, an otolaryngologist or otologist can usually fix it (surgery).

In the **inner ear** (cochlea) when the nerve cells are damaged, the child will have a permanent hearing loss. Some of the things that can cause damage to the nerve cells are:

1. Spinal meningitis: Bacterial, viral, or fungal infection or inflammation of the meningeal membrane surrounding the brain and spinal cord. Although a relatively uncommon occurrence, spinal meningitis may set in as a complication of untreated otitis media (Connelly, 1988).

2. Drugs: There are several drugs that adversely affect hearing. Parents need to ask their ear specialist which ones should be avoided in case their pediatrician or another doctor inadvertently prescribes one of these drugs.

3. Extremely loud noises: Sounds of sufficient intensity and duration can cause injury to the inner ear, producing a temporary or permanent hearing loss. Firecrackers, model airplanes tested indoors, toy firearms (caps), farm machinery, and extremely loud music are some of the sounds capable of producing injury. Consequently, it is important for the child to avoid exposure to these sounds.

4. Viral infections: Hearing loss may result from the mother having measles (rubella) during her pregnancy and/or other viral infections (such as cytomegalovirus) which can damage the baby during pregnancy or during the birth process.

5. Heredity: In most cases of hereditary deafness, the cochlea is damaged.

6. Rh factor: Due to blood incompatibility of mother and infant, damage in the cochlea may ensue. Often the brainstem is also damaged.

7. Syndromes (childhood deafness associated with defects): Various syndromes are associated with malformations of the inner ear (Waardenburg, Klippel-Feil, etc.). Some syndromes are characterized by both malformed low-set ears and damage to the middle ear and/or inner ear (CHARGE, Pierre Robin, etc.). Many syndromes include eye and kidney disorders. Progressive hearing loss is also possible.

The causes of about 40% of inner ear hearing losses are not known. Basically, problems in the inner ear cannot be corrected with surgery. A great deal of research is going on in the area of **cochlear implants** (sending electrical stimulation directly to the auditory nerve). Several implantation schemes are under investigation (inside the cochlea, at the oval window, etc.). Investigators have reported that electrical stimulation does produce auditory sensations and discrimination of loudness changes within normal limits. However, discrimination among frequencies (pitch) is poor. Word recognition skills of implanted patients (mostly adults) vary. There seems to be agreement that the use of implanted devices helps adult patients, who learned language before they lost their hearing, to control their own speech output and to engage in speech reading.

At the present time, cochlear implants for children are classified by the FDA as investigational devices. A lower age limit of two years is generally appropriate for being considered a candidate for a cochlear implant. There are not studies that adequately separate the effect of the implant from improvement due to maturation and training. The cochlear implant is an important step in the long-range goal of understanding, preventing and treating hearing impairment. The foremost limitation is that implantation does not restore normal hearing. It is likely that the future will bring significant improvements in this field of research.

Whatever causes damage to the cochlea or nerves to the brain may also cause damage to the **balance mechanism**, the semicircular canals. When this occurs, gross motor skills will be delayed and the infant may try to use sight and touch to compensate for damage to the balance mechanism.

Many multisensory impaired children have damage in the **brainstem** resulting in a problem with the way sound information is sent to the brain (auditory cortex). This could happen because of the following:

1. anoxia (lack of oxygen at birth);
2. maternal rubella;
3. birth trauma;
4. prematurity;
5. drugs;
6. Rh problem (incompatibility); and
7. encephalopathic diseases (brain diseases).

These same conditions can also damage the **auditory cortex** itself [refer to Figure H-6]. When the auditory cortex is damaged, the child may have difficulty analyzjng sounds, inhibiting inappropriate motor responses to sound, understanding sounds, remembering sounds, forming an auditory "space" (finding where a sound comes from and reasoning its location), and choosing which sound to listen to.

Some multisensory impaired children may also have suffered damage to other parts of the **brain** by the same mechanism that caused hearing loss. If the frontal lobe is injured, a child may have expressive aphasia which is the inability to produce language (understanding of language may not be affected). If the parietal area of the brain is damaged, a child may experience difficulty thinking about his experiences and thus be unable to make use of language. These children sometimes are diagnosed autistic. Whenever the temporal lobe of the brain is damaged, a child will be unable to attach meaning to sound and/or attend to sound.

It is often very difficult to diagnose specific brain disorders. The important issue at this point is not to waste time trying to label but to take advantage of these early years and begin stimulating the hearing system.

Cause Of The Child's Loss, If Known

Here is the location of your child's hearing problem [point to the outer, middle, inner ear, brainstem, and/or brain on Figure H-4]. The cause of your child's hearing loss is [discuss the cause of the child's loss if known, such as damaged nerves, fluid in the middle ear, brain damage, or combinations of these].

SAMPLE ACTIVITIES

none

SAMPLE CHALLENGES

1. Explain the location and cause of your child's hearing loss to your spouse (if not in attendance) or other family member.

REFERENCE AND READING LIST

1. American Auditory Society. (1988). Cochlear implant consensus statement: A preliminary draft, NIH Consensus Development Conference. *Corti's Organ*, *11*, 7.

2. Connelly, S. (1988). All about ear infections. In *Parenting Advisor*. Knoxville, TN: Whittle Communications.

FIGURE H-3

PROFESSIONALS INVOLVED WITH THE HEARING IMPAIRED

1. Otolaryngologist (ENT) or Otologist:

A physician (M.D., D.O.) knowledgeable in diseases of the ear, whose goal is to establish the medical characteristics of an individual's hearing loss and offer appropriate treatment recommendations. FTC (Federal Trade Commission) regulations require physician approval prior to the purchase of a hearing aid; either the otolaryngologist or otologist is the best qualified physician to do this. The intent of the medical examination is to assure that your child's best medical interests are protected prior to the purchase of a hearing aid. An otologist is a trained otolaryngologist (ear, nose and throat specialist) who has specialized in the ear.

2. Audiologist:

A professionally trained individual with a masters (M.A., M.S.) or doctorate (Ph.D., Ed.D.) degree in audiology. The audiologist has the basic responsibilities to assess hearing, determine the person's ability to use hearing, and to increase the ability of the hearing handicapped individual to cope with the situations of everyday life (through hearing aids, assistive listening devices, etc.).

3. Dispensing Audiologist:

An audiologist who, in addition to selecting a hearing aid and providing subsequent follow-up care, orders the hearing aid and sells it to the patient.

4. Hearing Aid Dispenser:

A person with no special training who obtains hearing aids directly from the manufacturer and sells them to patients upon receipt of a prescription from a physician or audiologist. This person does not have direct contact (except written) with the patient. Many audiologists have begun offering this service to patients. Some physicians offer this as well.

5. Hearing Aid Dealer:

A hearing aid salesperson who provides a retail outlet for hearing aids. A dealer is not an audiologist and is not trained to provide audiological services.

Figure H-4

ANATOMY OF THE HEARING SYSTEM

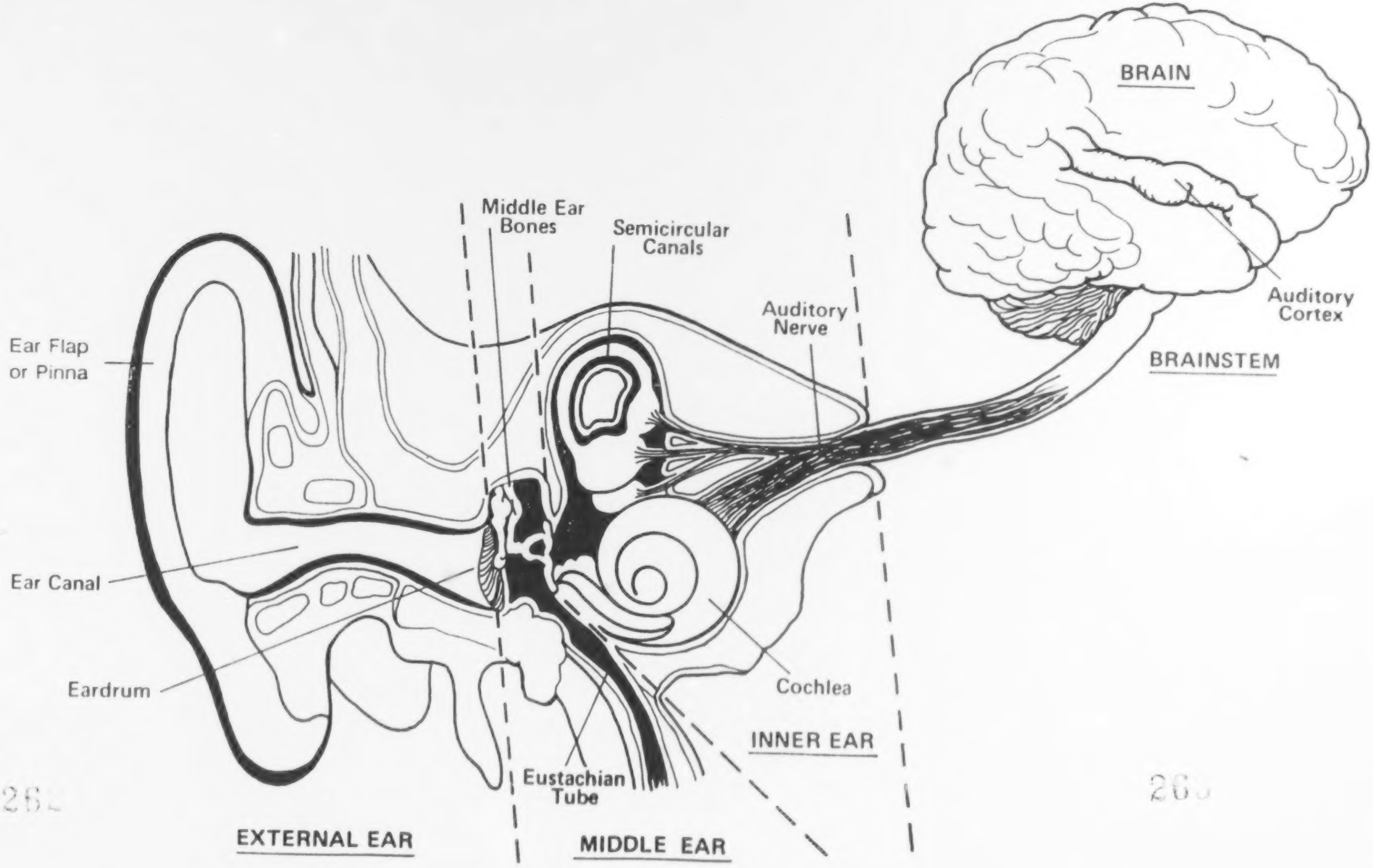
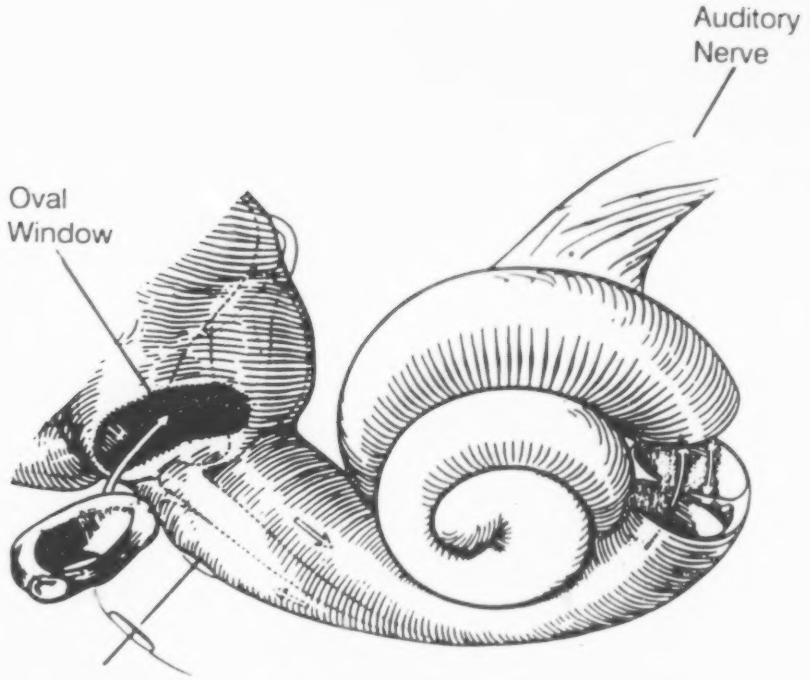

BRAIN
Middle Ear Bones
Semicircular Canals
Auditory Nerve
Auditory Cortex
BRAINSTEM
Ear Flap or Pinna
Ear Canal
Eardrum
Cochlea
INNER EAR
Eustachian Tube
EXTERNAL EAR
MIDDLE EAR

Figure H-5

The Cochlea


Auditory
Nerve
Oval
Window

ANATOMY OF THE COCHLEA

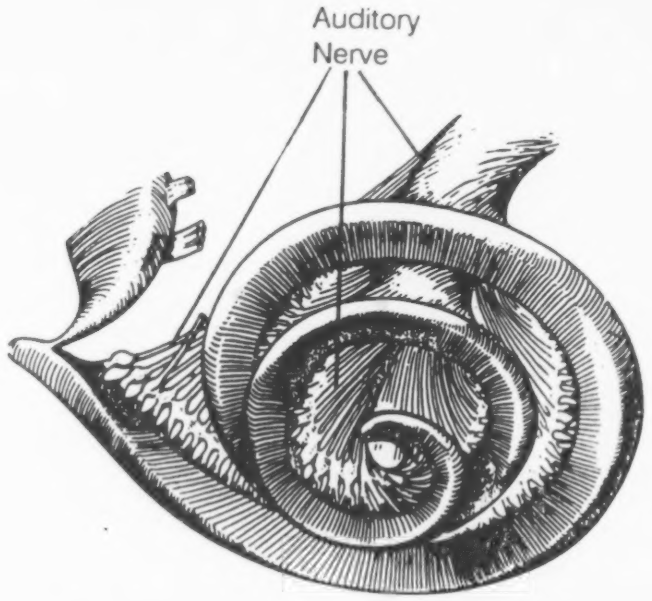
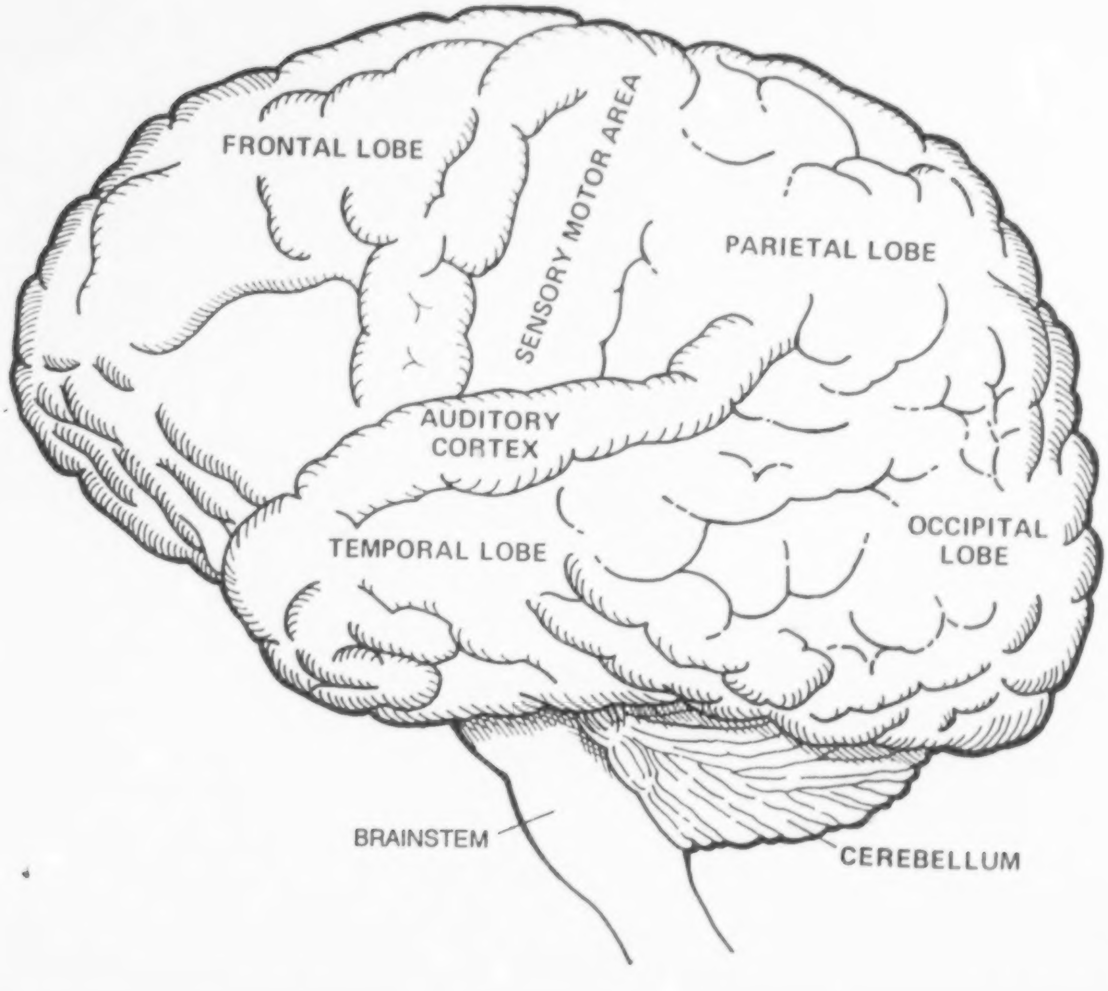

Auditory
Nerve

ILLUSTRATION OF INTERIOR OF THE COCHLEA SHOWING THE NERVE CELLS

Figure II-6

ANATOMY OF THE BRAIN


FRONTAL LOBE
SENSORY MOTOR AREA
PARIETAL LOBE
AUDITORY CORTEX
TEMPORAL LOBE
OCCIPITAL LOBE
BRAINSTEM
CEREBELLUM

TOPIC 4: MEASURING HEARING LOSS

PARENT GOAL

Parents will explain their child's hearing loss in terms of:

A. amount (mild, moderate, etc., or in dB);
B. configuration or shape (sloping, flat, rising); and
C. discomfort or tolerance level (does/does not have a tolerance problem).

MATERIALS

- Figure H-1 (in Topic 1)
- Figure H-7, "Sample Audiogram" (parent advisor may want to copy so she can write on it)
- Figure H-8, "Two Illustrations Of Hearing Loss With A Flat Audiogram"
- Figure H-9, "Two Illustrations Of Hearing Loss With A Sloping Audiogram"
- Figure H-10, "Impedance Testing/What Do Different Tympanograms Mean?"
- Figure H-11, "Auditory Brainstem Responses"
- Figure H-12, "Air Conduction Testing"
- Figure H-13, "Bone Conduction Testing"
- Figure H-14, "Illustration Of Conductive Hearing Loss"
- Figure H-15, "Illustration Of Sensorineural Hearing Loss"
- audiometer (if possible)
- child's own audiogram and other audiological test results
- patterns for vests, carrier pockets, and/or toupee tape

INSTRUCTIONS TO PARENT ADVISOR

If appropriate, describe how the audiologist determines if the child has a conductive loss (problem in the outer or middle ear) versus a nerve loss (problem in the inner ear). For most parents, the explanation will be difficult. Parent advisors may want to give it to interested parents only. A sample discussion is given in Supplemental Information For Parents at the end of this discussion.

If the child will be fitted with hearing aids on a trial or diagnostic basis, utilize the sample discussion also given in Supplemental Information For Parents. The guidelines for the introduction of hearing aids (Topic 7) and the auditory stimulation activities in the Auditory Development Section (pages 393 to 397) should be utilized prior to any decision being made that wearable amplification is not appropriate.

Utilize the child's own audiological evaluation, the sample discussion below, and Figures H-7 through H-14 to help the parents meet the goals for this topic. It is a good idea to review this information with the parents each time the child returns for an audiological evaluation. Remember to select and present only the portions of this topic which are applicable to the particular child and family.

SAMPLE DISCUSSION

Hearing Testing

You will remember when your child had his hearing tested, the audiologist wrote down what your child could hear on a paper that looked like this. This is called an audiogram [show sample audiogram in Figure H-7]. Let's talk about how the audiologist tests hearing and what an audiogram is. When your child has his hearing tested, the audiologist first wants to know what kind of response your child makes to sound and second how loud a sound must be for him to hear it. First, the audiologist will observe your child's general level of awareness to the environment. The audiologist will be on the lookout for responses to touch (tactile), to light (visual), and to sound (auditory). While the audiologist is observing, she will want you to describe the changes in your child's behavior, observed by you at home, that seem to signal responses to sound; for example:

1. startle responses;
2. eye blink;
3. change in ongoing behavior (either increase or decrease of activity);
4. tensing of entire body;
5. orienting or searching for sound;
6. smiling;
7. head turn;
8. vocalization response (grunt, change in sucking, babbling);
9. negative or withdrawal response; and
10. inconsistent response.

The audiologist will also want you to describe the circumstances under which responses to sound are noted (for example, only when your child is in his support chair or only when it is completely quiet in the room), what specific sounds your child responds to (noises, voices, etc.), and how consistently he responds to these sounds (e.g. once only, over and over, only when not watching something).

Second, the audiologist will use what is called behavioral observation audiometry in the sound field room (sound comes through speakers) and under earphones to determine how loud sounds need to be for your child to hear them. The audiologist will utilize a variety of sounds (e.g. speech, environmental sounds, music, and sound toys). These sounds are recorded on a tape and then played through an audiometer where the loudness (intensity) can be regulated. The audiologist may also use tape recorded speech calibrated or filtered at a certain pitch.

The audiologist will pick one of these sounds with one frequency (pitch) like 1000 Hz which is here on the audiogram [show Figure H-7]; lower pitches are here, and higher pitches are here. She will send the 1000 Hz sound to your child very softly. This side of the audiogram tells us how loud the sounds are. Very soft sounds are here, very loud sounds are here [point out]. So the audiologist gives your child a 1000 Hz sound very softly (maybe 10-15 dB). Your child cannot hear the sound so he does nothing. Then the audiologist makes the sound louder and louder. When your child hears the sound, he will blink or turn his head or decrease his activity or in some way let the audiologist know he hears the sound.

If your child hears the sound when it is 80 dB loud, the audiologist will make a mark at 80 dB [point out]. If he hears the sound at 95 dB, the audiologist will make a mark at 95 dB [point out]. When the audiologist gives your child a sound in only one of his ears, she will send the sound into just one earphone. If your child hears the 1000 Hz sound in his right ear at 80 dB, the audiologist will make a circle like this at 80 dB [demonstrate]. If your child hears this sound in his left ear at 90 dB, the audiologist will make an "X" like this at 90 dB [demonstrate]. The audiologist will then select another pitch, maybe an octave above 1000 Hz or 2000 Hz [point out], and make that sound loud enough for your child to hear it. When the speakers are being utilized, the audiologist will mark an "S" [demonstrate] and you will know that at least one ear is hearing the sound at this level. The only way to find out about each ear is to use earphones.

It is not likely that a complete test (responses at every frequency) will be obtained during one evaluation period. Usually several visits to the audiologist are required. Initially, a multihandicapped sensory impaired infant may have only primitive or reflexive responses such as startle or eye-blink. As your child develops, it may be possible to "condition" a response to sound. This means he can be taught to look at an animated toy or blinking light each time he hears a sound. He is rewarded for looking each time he hears by getting to see the toy or light. Thus, he continues to look each time he hears. This procedure is appropriate for most visually impaired (not totally blind) children. When a conditioned response to sound can be established, pure tones (sounds with only one frequency or pitch) can be used to obtain a complete audiogram. Once responses to all the pitches important for hearing speech can be obtained, the audiologist will have a picture that looks like this [complete a sample audiogram]. This audiogram is now complete. If a child does not hear the sound even when it is presented at the limit of the audiometer (which is 110 dB on some audiometers and 120 dB on others), the audiologist may not make a mark or may use the audiometric symbols O↙ and X↘ indicating no response.

Some people have the same amount of hearing at each pitch. Their audiogram may look like this [show Figure H-8]. Some people have different amounts of hearing at each pitch. Their audiogram may look like this [show Figure H-9].

Additional Audiological Tests

The audiologist may also use additional tests such as impedance audiometry (tympanometry) to help determine what kind of loss (conductive or sensorineural) your child has. The impedance testing may also help determine:

1. existing middle ear pressure (air pressure in middle ear versus outer ear);

2. eardrum mobility or movement (can eardrum still move when sound strikes it?);

3. eustachian tube function (is tube open so air can get into the middle ear?);

4. continuity and mobility of the middle ear bones (are bones properly connected to each other and moving when sound strikes them?); and

5. acoustic reflex thresholds (does middle ear muscle contract when a loud sound is presented?).

Tympanometry is the technique for measuring the movement (mobility) of the eardrum which in turn gives information about almost any problem in the eardrum or middle ear. For example, if there is negative pressure in the middle ear (less air in the middle ear than the outer ear), this may cause the eardrum to be pulled into the middle ear cavity (retracted) and cause a mild conductive type hearing loss. This information can be detected by tympanometry (impedance testing) even though there may be no observable fluid in the child's middle ear [use Figure H-10 to discuss child's particular impedance results].

The acoustic reflex threshold is the loudness level (dB) at which the stapedial muscle contracts. The stapedial muscle is the little muscle in the middle ear going from the stapes bone out to the wall of the middle ear. It is known at what level the muscle contracts in normal hearing ears. The level at which reflexes are present, or their absence, gives the audiologist additional information about the kind (cochlea versus middle ear) and amount of hearing loss. This type of testing is very valuable for infants and young children who cannot cooperate fully in other diagnostic tests.

Remember, the pure tone test results may miss a middle ear problem when severe and profound sensorineural hearing losses exist. Therefore, it is important to "watch" for these with tympanometry and medical checkups of the ears.

In addition to these test methods, many multisensory impaired infants are evaluated with brainstem evoked response (BSER) audiometry, also called auditory brainstem response (ABR) audiometry. This procedure is helpful with many infants, particularly those who do not appear to respond to standard procedures. BSER is a recording of brain activity (electrical) for sound stimulation recorded via electrodes from the top of the head (vertex) to either mastoid (or earlobe) [show and discuss Figure H-11]. It is most easily evoked (produced, observed) with clicks repeatedly presented and then summated (or averaged) by computer analysis. These sound clicks are not frequency (pitch) specific and thus the evoked potential (electrical response) is not as specific as an audiogram. The latency of the potential (how long before it occurs after the click) corresponds to specific causes of hearing loss (middle ear versus cochlea versus auditory nerve problems). Despite the fact that children up through the age of three or four must be sedated to perform the test, it does give a reliable indication of the amount of hearing loss in each ear (up to the limits of the equipment) for frequencies above approximately 1500 Hz.

The Child's Own Audiogram

Let's look at your child's audiogram and talk about what he hears. At this very low pitch, your child hears at ___ dB. At this higher pitch, your child hears at ___ dB.

Of course, different people have different amounts of hearing. A person who has normal hearing can hear sounds that are 0-20 dB loud [refer to Figure H-1 in Topic 1, page 307]. A person who has a very small (mild) hearing loss can hear sounds when they are about 21-40 dB loud. If the sounds must be 41-70 dB, the person has a moderate loss. If the sounds must be 71-90 dB before they can be heard, that person has a severe hearing loss. A person who has a profound loss hears sounds only when they are 91 dB or louder. Your child's hearing loss is in this area [show on child's audiogram].

Clarity And Tolerance Testing

In addition to how loud sounds have to be for your child to hear, the audiologist is also interested in how clearly your child hears. For infants, judging how clearly one hears has to be accomplished by long-term observation of responses to sound. The most basic level is whether or not a child can perceive the difference between the presence or the absence of sound. Beyond this very basic skill, the audiologist looks for the ability to: (a) grossly discriminate between two very different sounds, (b) use sound in some systematic way, and (c) produce consistent responses to consistent sounds.

The last area the audiologist looks at is tolerance, or in other words, how loud the sound can be before your child gives signs of discomfort. It is important to get this information for each ear separately. If the audiologist cannot obtain a level, she will assume one within the range of safety for your child. If observations in the home indicate your child is not tolerating this level (startle responses to many sounds), your child may need a special adjustment in his hearing aid. The audiologist should be contacted and the aid adjusted or replaced as soon as possible.

SAMPLE ACTIVITIES

none

SAMPLE CHALLENGES

none

SUPPLEMENTAL INFORMATION FOR PARENTS

Conductive Loss Versus Nerve Loss

Pure tone testing is usually accomplished using two different methods of getting sound to the ear. Pure tone air conduction testing uses earphones. In air conduction testing, sound must travel through the entire auditory system as shown in Figure H-12. In general, if damage to the auditory system exists anywhere, the result will be some degree of hearing loss.

Pure tone bone conduction testing uses a bone vibrator which usually fits behind the ear. Vibration from the bone vibrator bypasses the external ear and middle ear and is transferred directly to the cochlea as shown in Figure H-13. Thus, if the inner ear can hear better than the entire auditory system (due to middle ear infection, external ear malformation, etc.), the bone conduction responses will be better than the air conduction responses. For example, if a 40 dB hearing loss exists as revealed by the air conduction responses shown in Figure H-14, but the bone conduction responses are normal (0-15 dB), the problem must necessarily lie in the external and/or middle ear. This type of hearing loss is referred to as a conductive hearing loss. In this example, the inner ear (cochlea) is functioning normally. On the other hand, if the pure tone air conduction and bone conduction responses are equivalent as shown in Figure H-15, the problem must necessarily lie in the cochlea. Such a hearing loss is referred to as a sensorineural loss. [Note: In case 2 on Figure H-15, bone conduction thresholds remain at 65 dB whereas the air conduction thresholds continue to drop since 65 dB (approximately) is the limit for bone conduction testing.] It is, of course, possible for a person to have hearing loss due to both conductive and sensorineural factors in the same ear or to have a conductive loss in one ear and a sensorineural loss in the other ear.

Diagnostic Trial Fitting of Hearing Aids

The purpose of a diagnostic trial hearing aid fitting is to observe the reaction of your child to amplified sound. This can help the audiologist determine whether or not your child has a significant hearing loss that warrants hearing aid use. Hearing aids that are set very softly are used initially. We will carefully observe your infant's responses, as will the audiologist, to his hearing aids. If your child's responses to sound improve with amplification, that is a good indication the aids are helping.

REFERENCE AND READING LIST

1. Franklin, B. (1976, April). *Audiological assessment of the deaf-blind and multihandicapped child.* Paper presented at the workshop Basic Assessment and Intervention with Deaf-Blind and Multihandicapped Children, Arizona State University.

2. McInnes, J. M., & Treffry, J. A. (1982). *Deaf-blind infants and children: A developmental guide.* Toronto: University of Toronto Press.

3. Northern, J. L., & Downs, M. P. (1978). *Hearing in children (2nd Edition).* Baltimore, MD: Williams and Wilkins Company.

4. Tait, C. (1977). Hearing and the deaf-blind child. In E. Lowell & C. Rovin (Eds.), State of the arts. Sacramento, CA: California State Department of Education.

Figure H-7

Sample Audiogram

KEY

O = RIGHT EAR
X = LEFT EAR
[] = BONE CONDUCTION
S = SPEAKER
A = AIDED

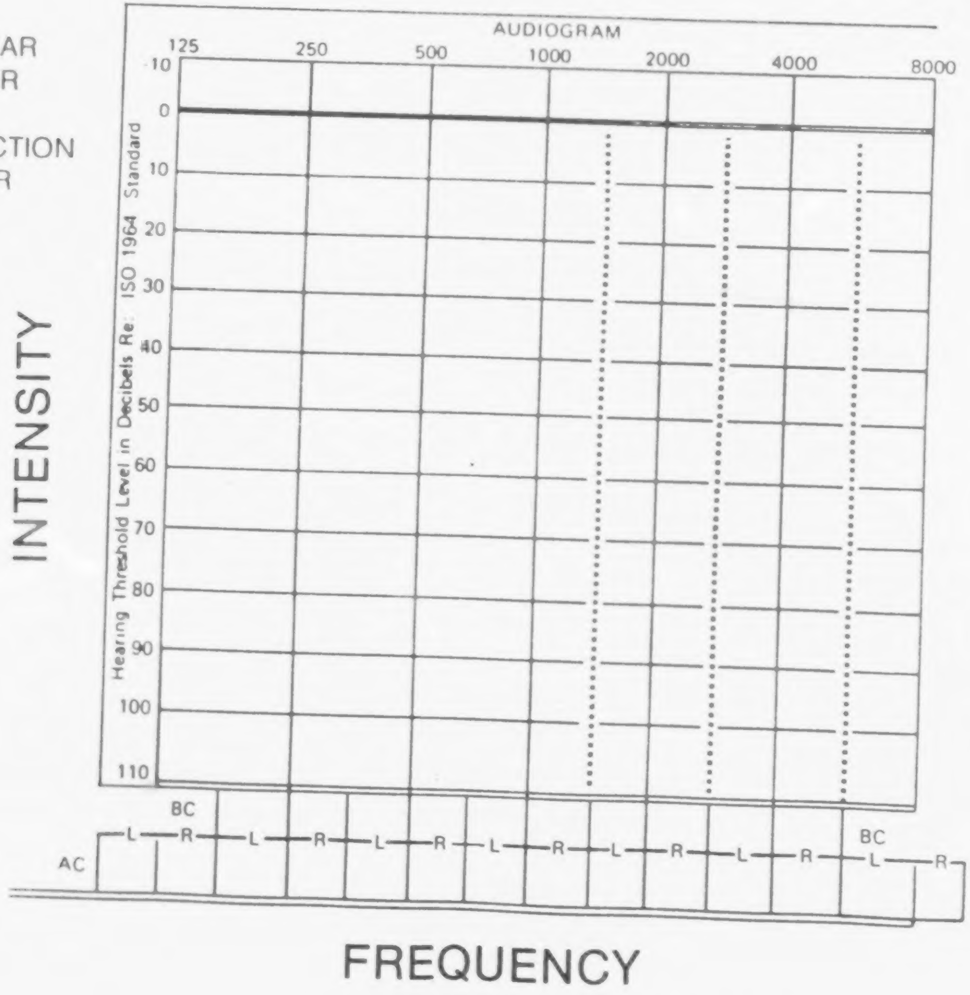


Figure H-8

Two Illustrations of Hearing Loss with a Flat Audiogram

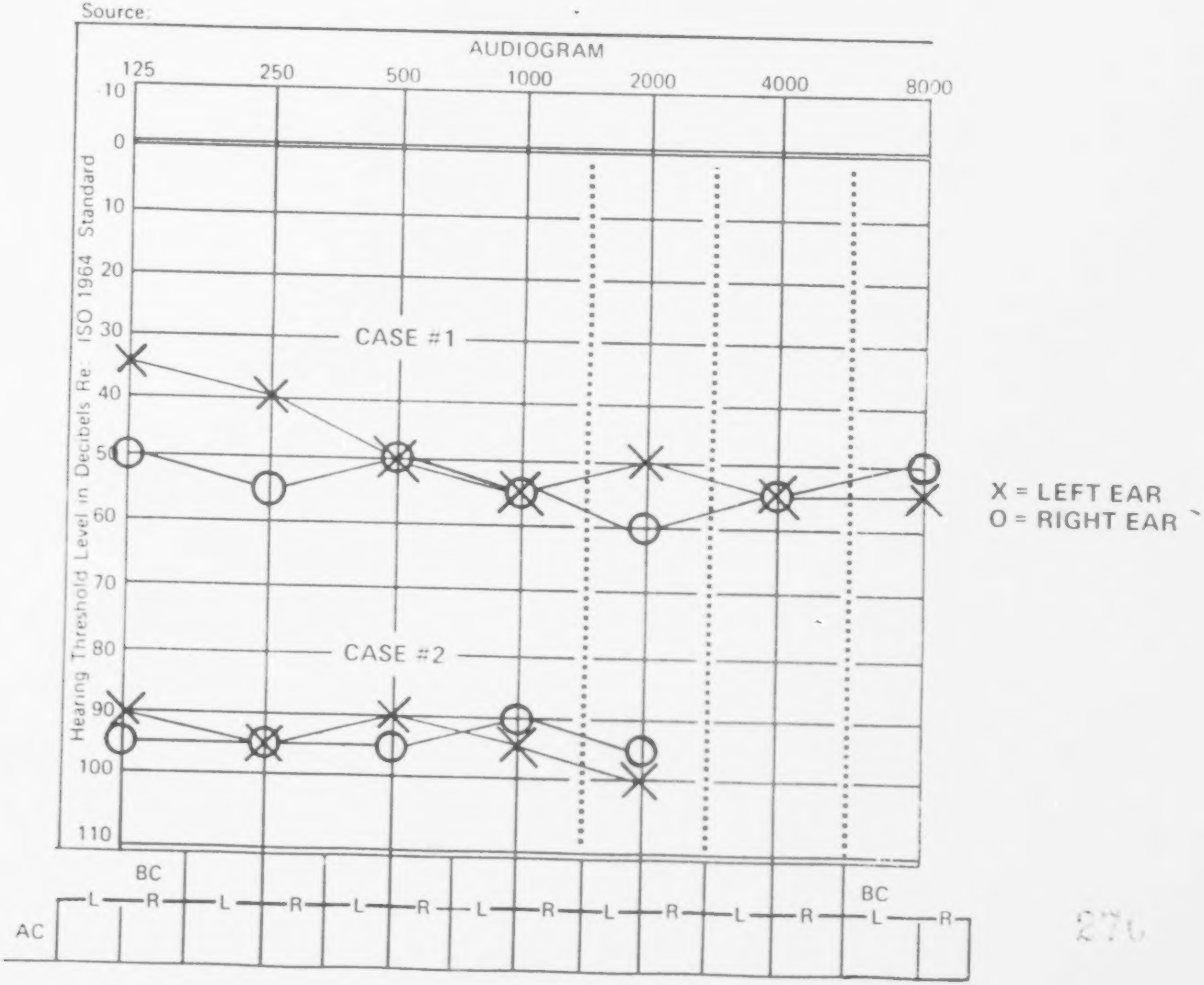


Figure H-9

Two Illustrations of Hearing Loss with a Sloping Audiogram

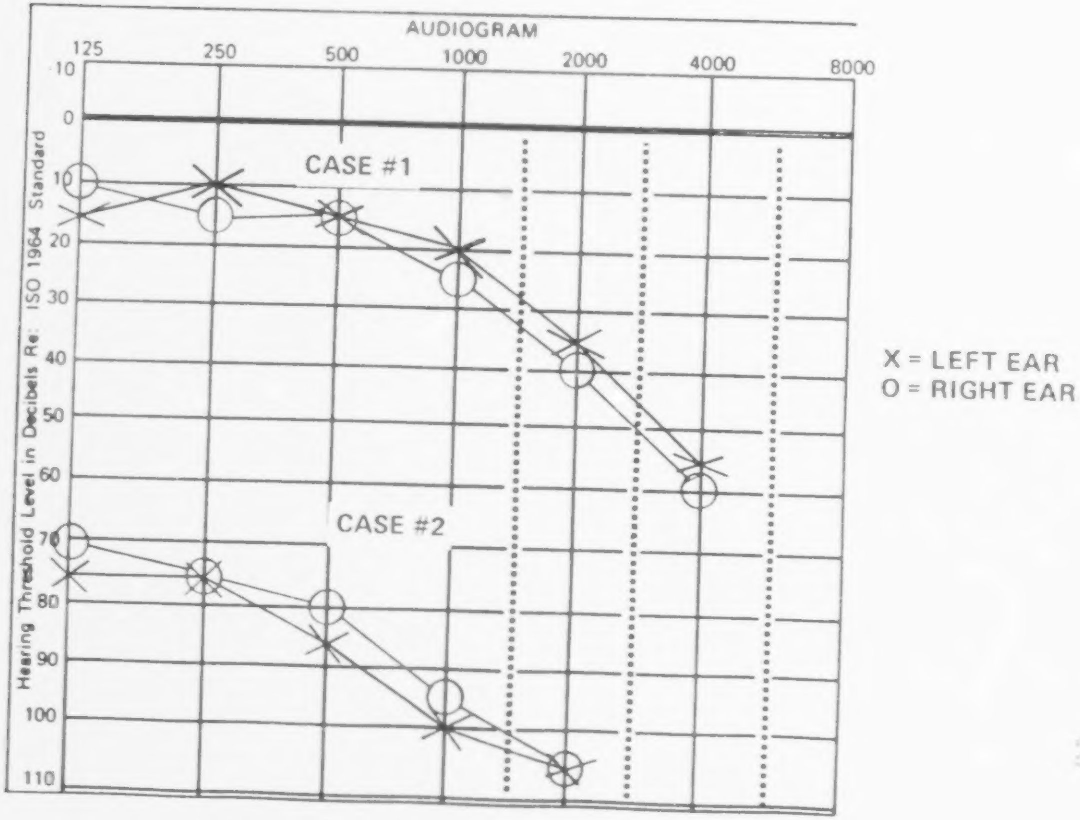


Figure H-10

Impedance Testing

What Do Different Tympanograms Mean?

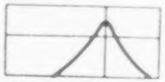
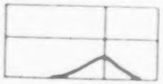
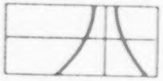
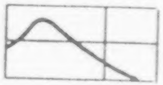
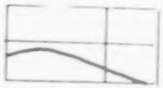
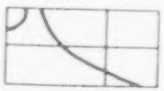
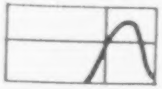
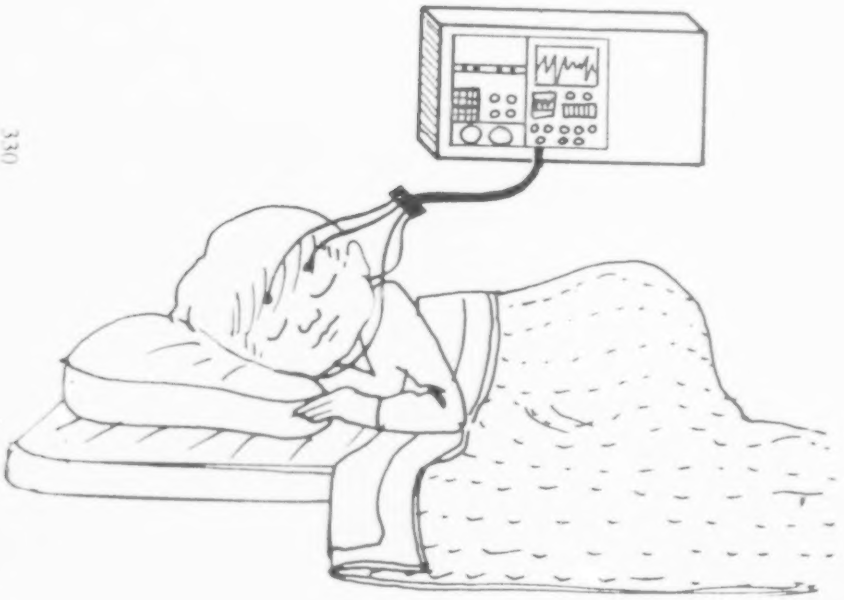
TYMPANOGRAM	PRESSURE	MOBILITY	MEANING
	Normal	Normal	Normal
	Normal	Low	Draining from the middle ear and/or thickened ear drum and/or immobile ossicle bones and/or fluid in the middle ear
	Normal	High	Floppy ear drum and/or broken ossicle bones
	Negative	Normal	High negative pressure (ear drum pulled into middle ear) with or without draining from the middle ear
		Low	Draining from the middle ear and/or thickened ear drum and/or immobile ossicle bones and/or fluid in the middle ear
	Negative	High	Floppy ear drum and high negative pressure (ear drum pulled into middle ear) or broken ossicles and high negative pressure
	Positive	Normal	High positive pressure (ear drum pushed out from middle ear) with or without draining from the middle ear

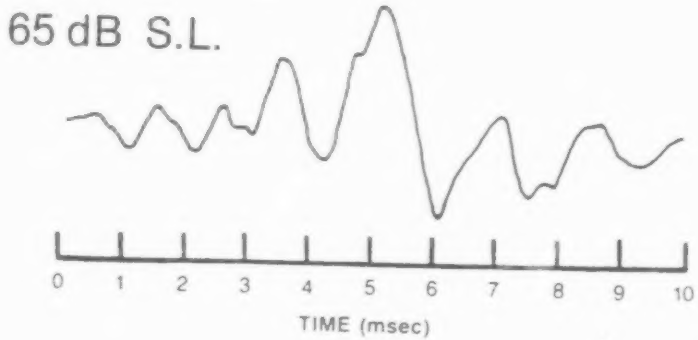
Figure H-11

Auditory Brainstem Responses (A.B.R.)

A.B.R. Testing



Normal A.B.R. Recording



A.B.R. Recording Showing No Response

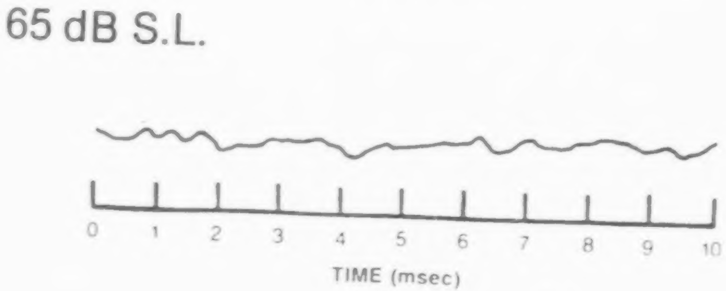
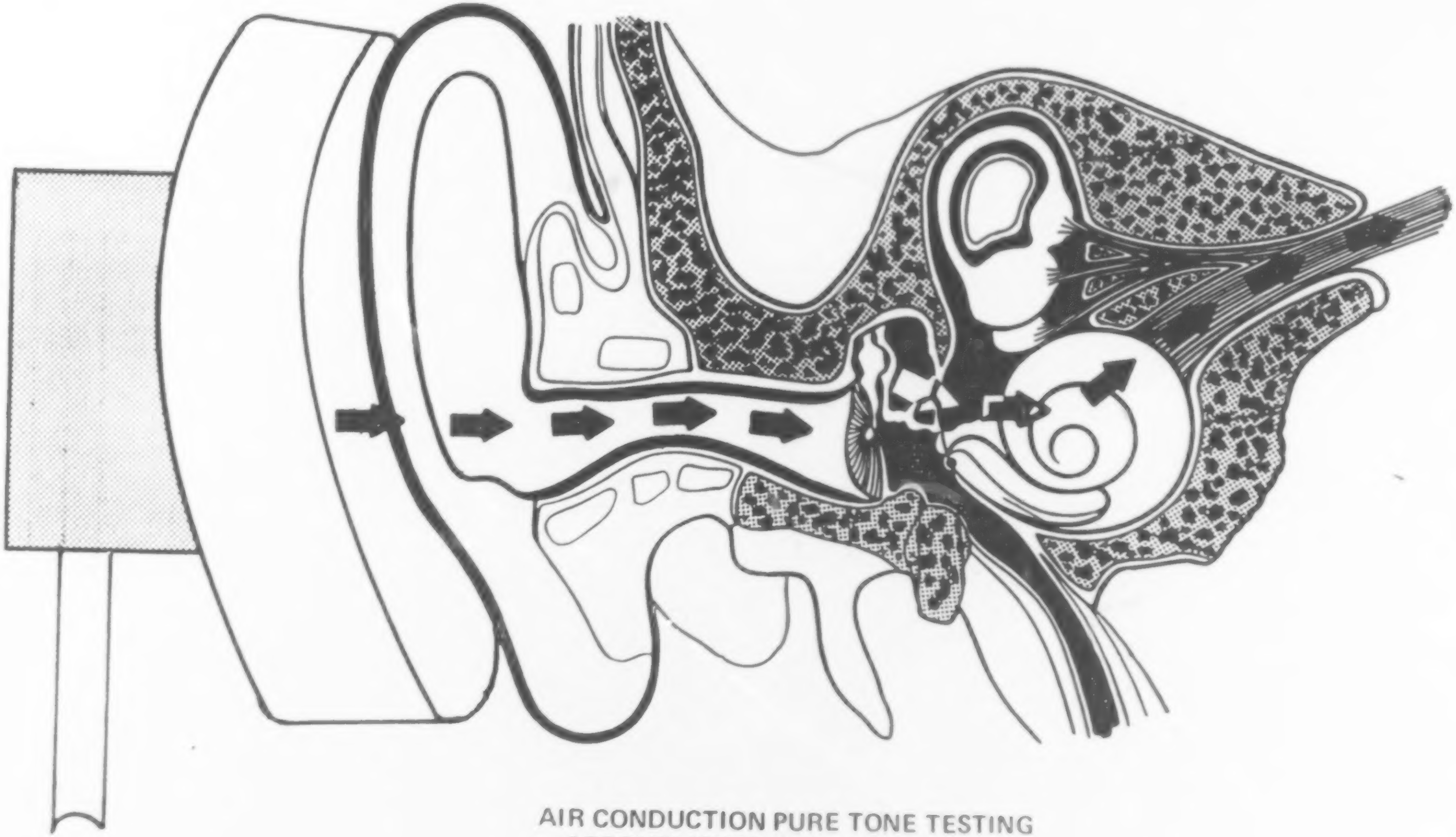


Figure H-12

Air Conduction Testing



AIR CONDUCTION PURE TONE TESTING
– ACCOMPLISHED WITH EARPHONES –

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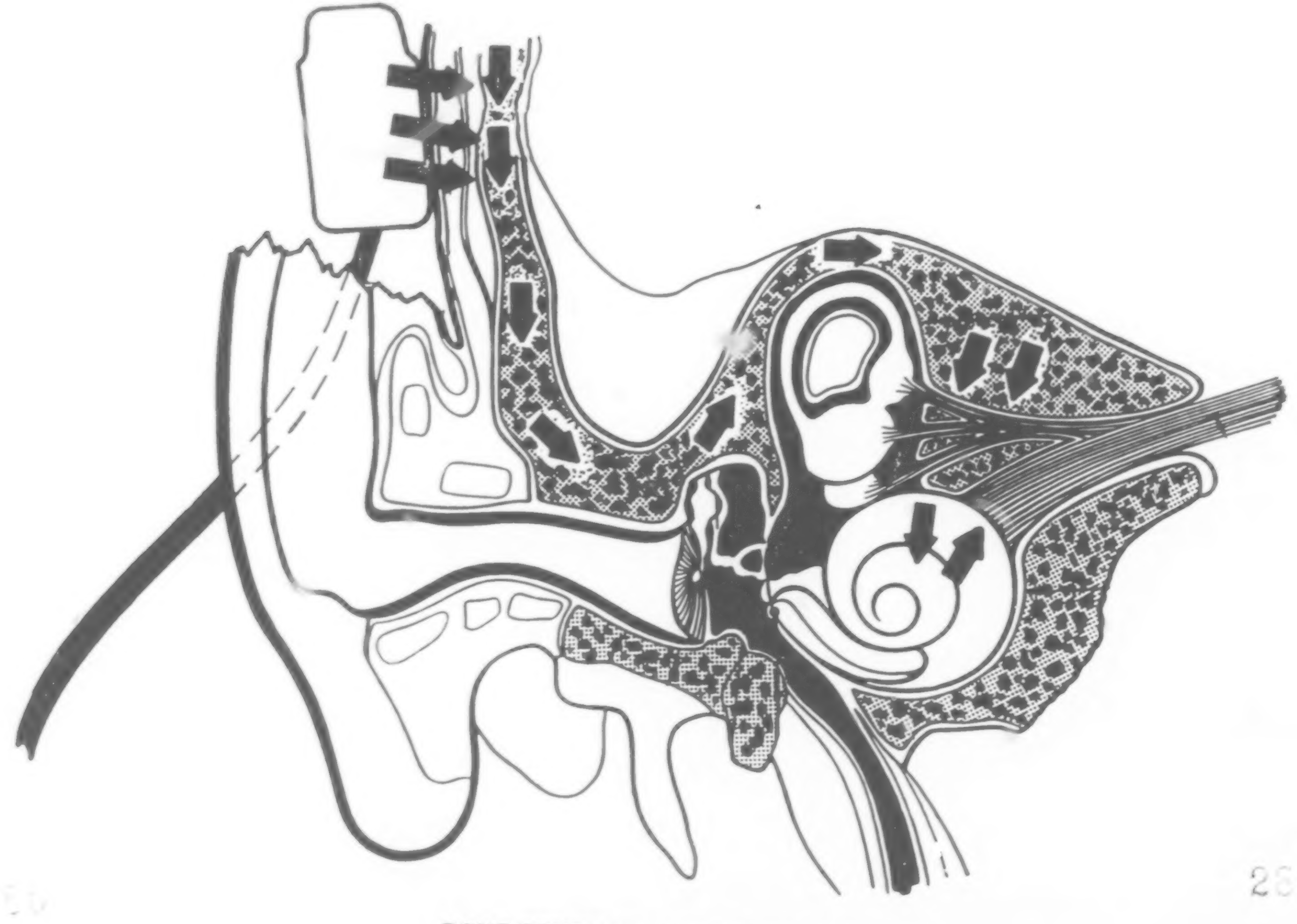
Figure H-13

Bone Conduction Testing



BONE CONDUCTION PURE TONE TESTING

Figure H-14

Illustration of Conductive Hearing Loss

X = LEFT EAR
O = RIGHT EAR
[] = Bone Conduction

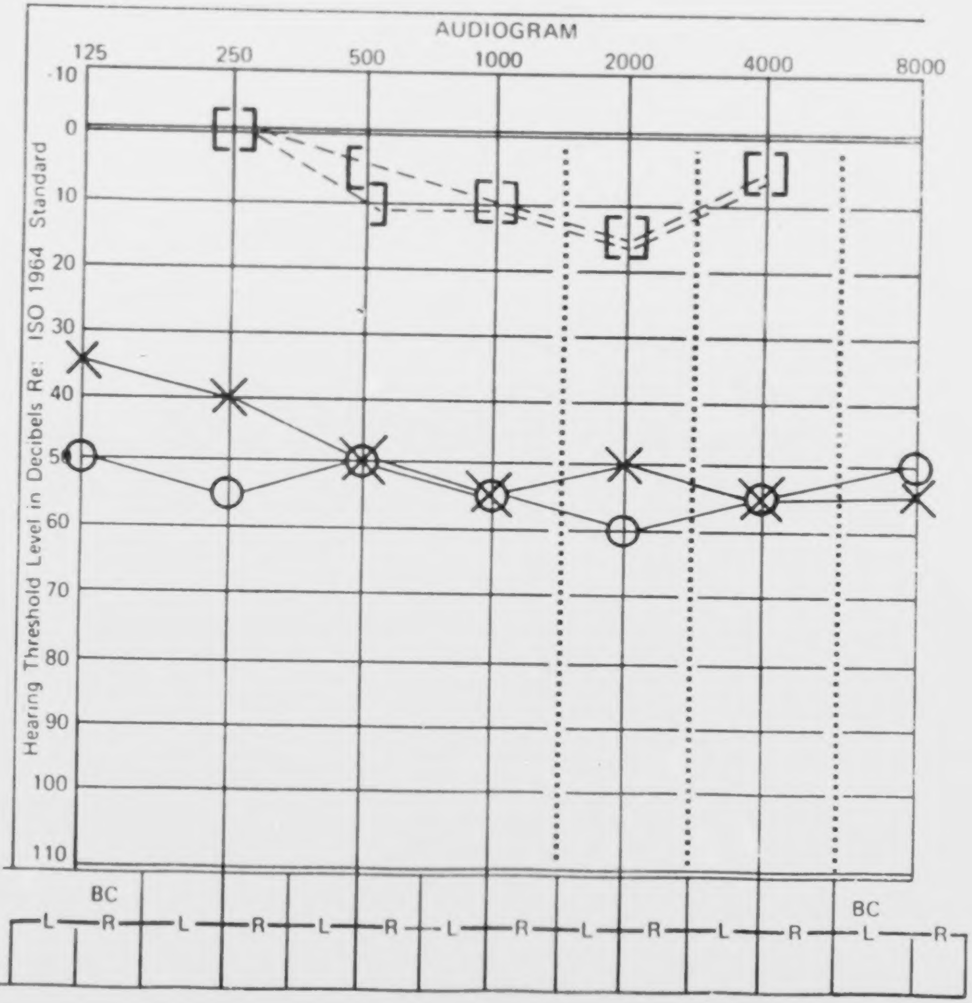
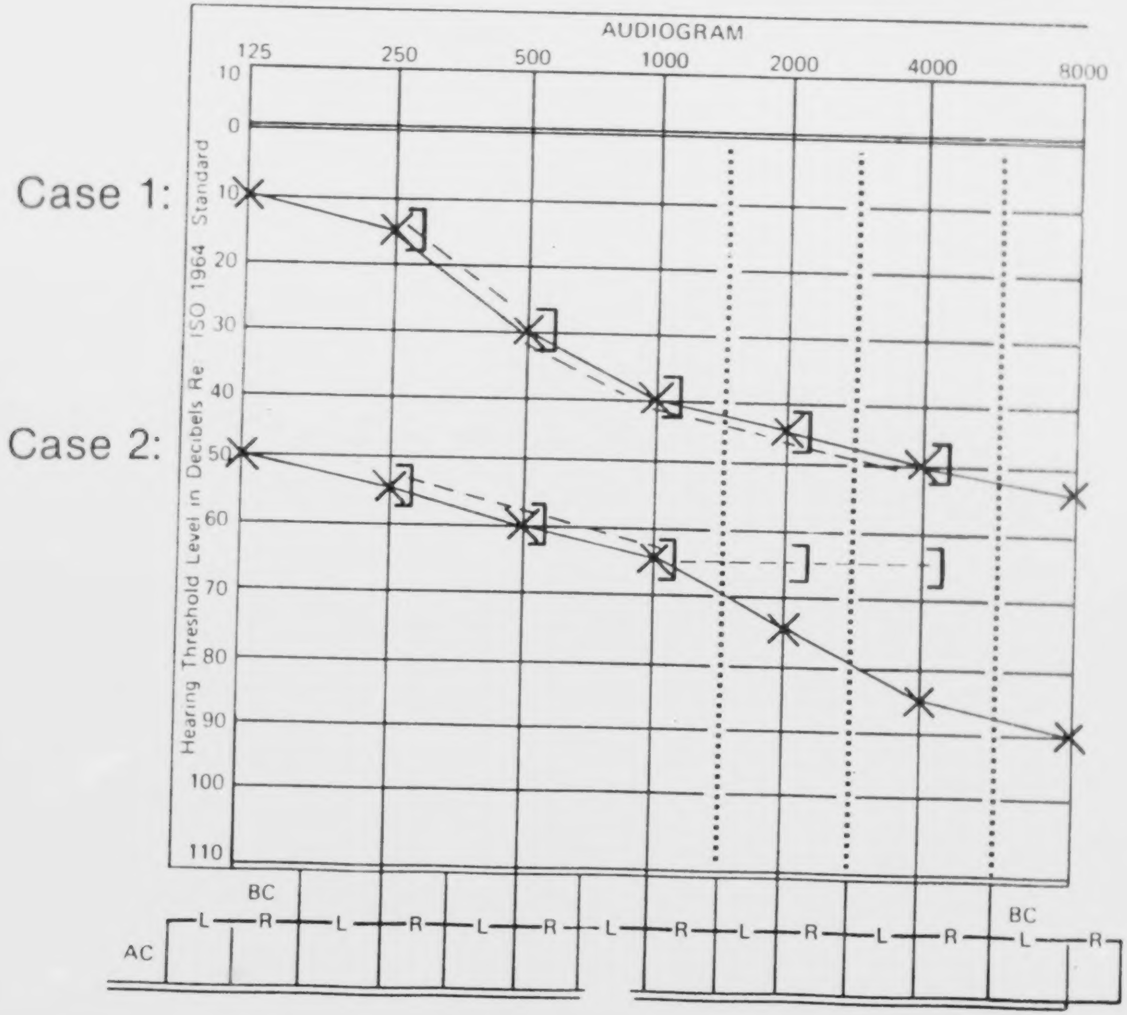


Figure H-15

Illustration of Sensorineural Hearing Loss



TYPES AND DEGREES OF HEARING LOSS

Types and Degrees of Hearing Loss

There are three types of hearing loss: Conductive, Sensorineural, and Cortical/Perceptual. For conductive and sensorineural hearing loss, there are four degrees (mild, moderate, severe, and profound). There are no degrees for cortical/perceptual hearing loss.

Types of Hearing Loss	**Degrees of Hearing Loss**
Conductive	Mild
	Moderate
	Severe
	Profound
Sensorineural	Mild
	Moderate
	Severe
	Profound
Cortical/Perceptual	

Conductive Hearing Loss:

This hearing impairment is due to a disruption of the transmission of sound through the outer and middle ear.

What are some of the causes of this type of hearing loss?

This type of hearing loss can be caused by:
- blockage of the ear canal (by wax, some foreign object, etc.);
- blockage of the eustachian tube opening (by infection, allergy, etc);
- damage to the eardrum (by infection, blow to the heard, puncture by foreign object, etc.);
- damage to the three tiny bones in the middle ear (infection, etc.);
- congenital malformation of the middle ear (Pert's syndrome, Treacher Collins, Pierre Robin, etc.);
- congenital malformation of the outer ear; and,
- any other situations that affect the outer and middle ear's ability to transmit sound waves to the inner ear.

How does this type of hearing loss affect hearing?

1. Sounds seem dull with little volume, there is a reduction of sound of all frequencies.
2. Sounds that are heard are not distorted.
3. Most speech sounds can be heard but are softer.
4. Words and sentences can be heard and understood with amplification.

What can be done?

1. Excess wax can be removed - by a physician or nurse.
2. The foreign object can be removed - by a physician or nurse.
3. There is some treatment that can be done such as providing medication for allergies and infections; lancing the eardrum to drain fluid from the middle ear; inserting tubes to equalize pressure between the outer and middle ears; and surgically repairing a damaged eardrum.
4. There are also some treatments for some genetic disorders such as providing prosthetic ossicles (the tiny bones of the middle ear) and other surgery.

5. A hearing aid is also often used.

Sensorineural Hearing Loss:

This hearing impairment is due to sensory or nerve damage in the inner ear, the auditory nerve, and/or the brain stem.

What are some of the causes of this type of hearing loss?

This type of hearing loss can be caused by:
- illness (such spinal meningitis - bacterial, viral, and/or fungal, rubella, and other viral/bacterial/fungal infections);
- hereditary (in most cases is it damage to the cochlea);
- Rh factor;
- trauma;
- extremely loud noises;
- syndromes (CHARGE Association, Waardenburg, Pierre Robin, etc.);
- drugs (pre and/or post);
- prematurity; and,
- anoxia (lack of oxygen at birth).

How does this type of hearing loss affect hearing?

1. There is a hearing loss starting with high frequencies.
2. Perceived volume of sound can be severely reduced.
3. Sounds tend to be distorted - even with hearing aids.
4. Not all speech sounds can be heard.
5. Words and sentences can be difficult or impossible to understand through listening alone.

What can be done?

1. Hearing aids can be used - but they only amplify the sound, not improve the quality of the sound.
2. Cochlear implant - may or may not really work for the person. This only improves detection of sound; it does not guarantee recognition of sound without speechreading.

Cortical/Perceptual Hearing Loss:

This hearing impairment is due to damage to the auditory cortex and/or other parts of the brain used to process sound (such as the frontal lobe, parietal lobe, etc.).

What are some of the causes of this type of hearing loss?

This type of hearing loss can be caused by:

- anoxia (lack of oxygen at birth);
- prenatal infections (such as rubella, etc.);
- birth trauma;
- post natal trauma;
- prematurity;
- drugs (both pre- and post natal);
- Rh factor; and,
- brain diseases

How does this type of hearing loss affect hearing?

This depends on which part of the brain is affected.

If the auditory cortex is affected, the person may have difficulty analyzing sounds, remembering sounds, and choosing which sound to attend.

If the frontal lobe is affected, the person may have expressive aphasia which means that person can understand language but not be able to produce it.

If the parietal lobe is affected the person may be unable to process experiences and therefore not be able to use language.

If the temporal lobe is affected, the person may not be able to attach meaning to sound and/or attend to sound.

Figure II-4

ANATOMY OF THE HEARING SYSTEM

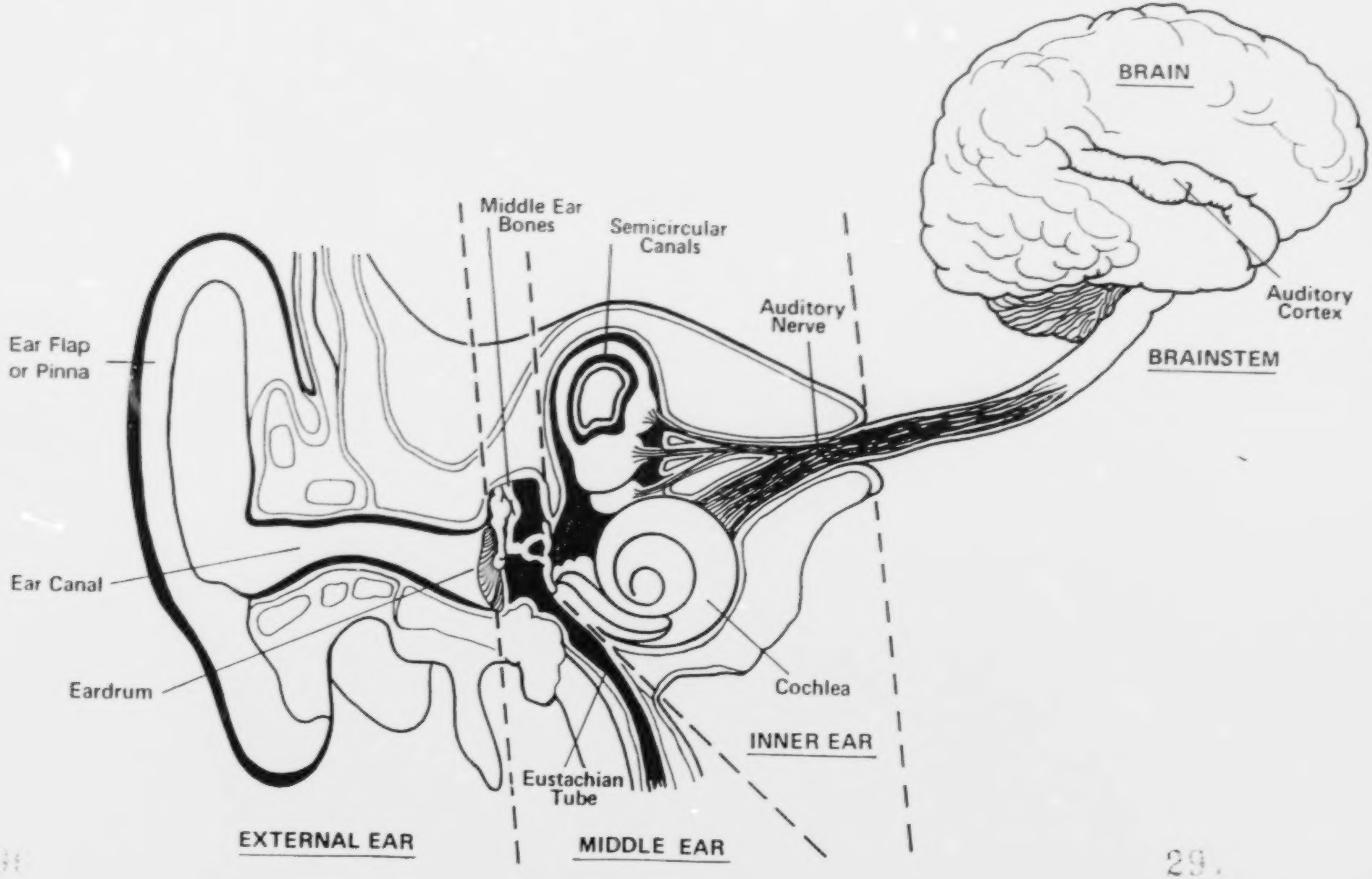
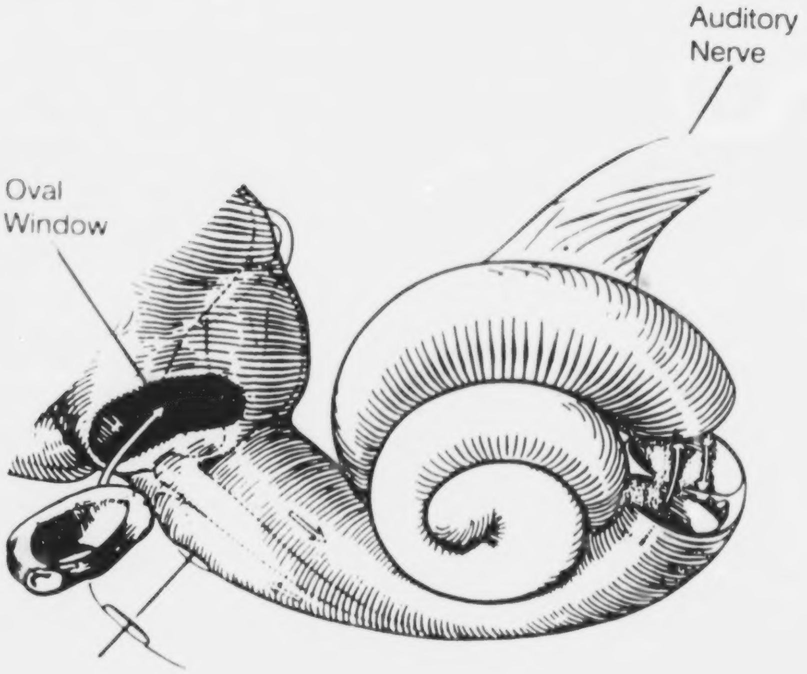

BRAIN
Middle Ear Bones
Semicircular Canals
Auditory Nerve
Auditory Cortex
BRAINSTEM
Ear Flap or Pinna
Ear Canal
Eardrum
Cochlea
INNER EAR
Eustachian Tube
EXTERNAL EAR
MIDDLE EAR

Figure II-5

The Cochlea


Auditory
Nerve
Oval
Window

ANATOMY OF THE COCHLEA

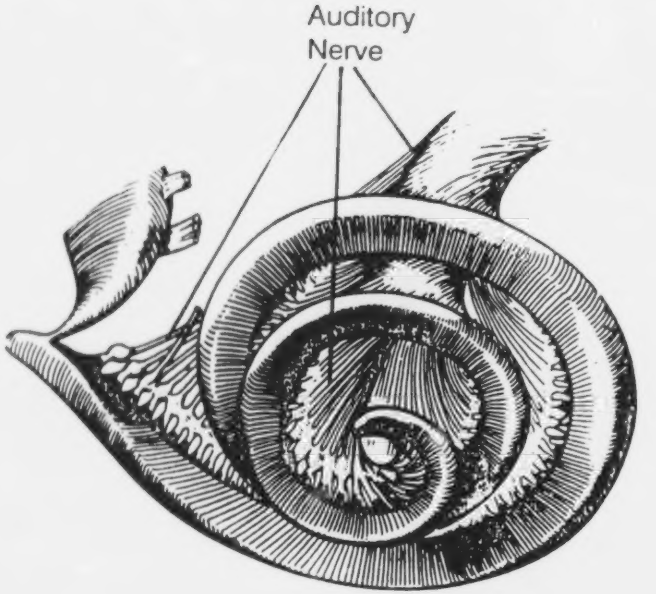

Auditory
Nerve

ILLUSTRATION OF INTERIOR OF THE COCHLEA SHOWING THE NERVE CELLS

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Figure H-6

ANATOMY OF THE BRAIN

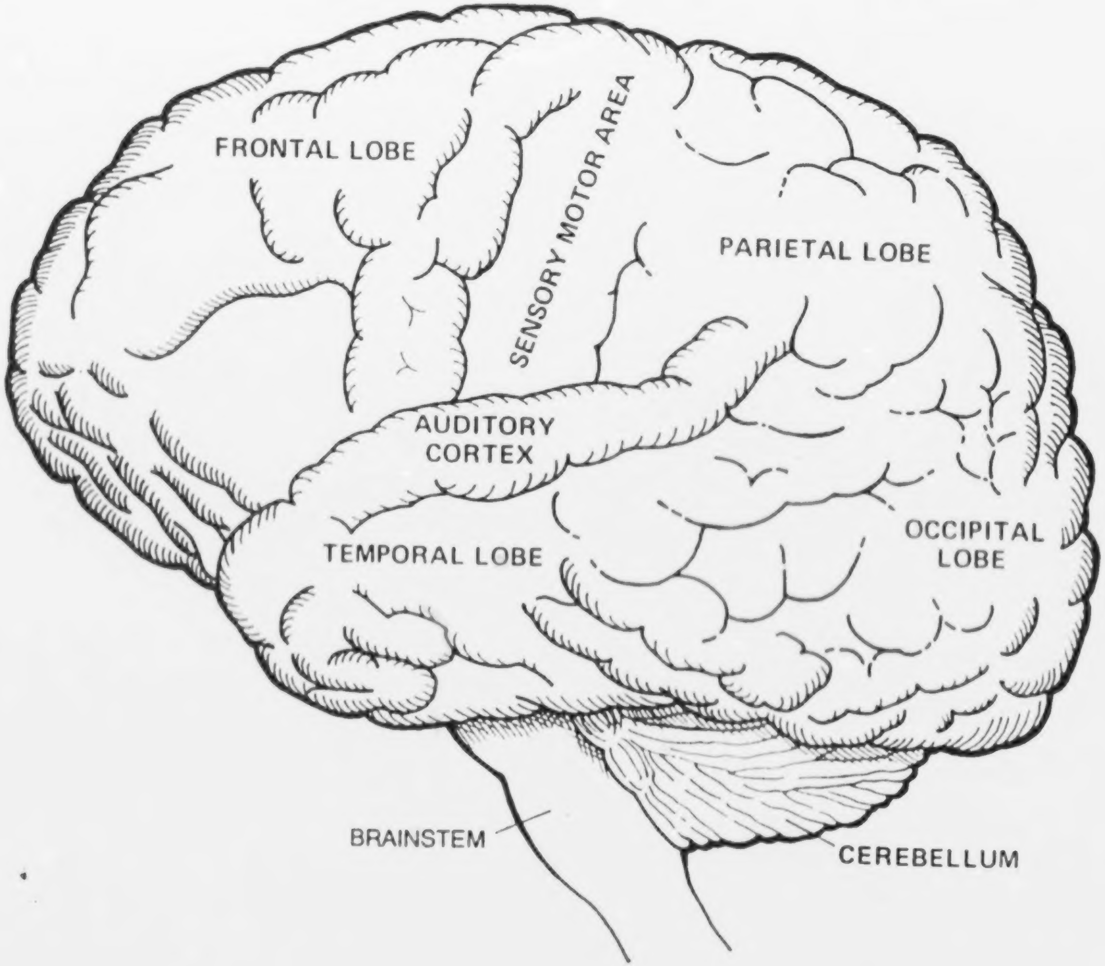

FRONTAL LOBE
SENSORY MOTOR AREA
PARIETAL LOBE
AUDITORY CORTEX
TEMPORAL LOBE
OCCIPITAL LOBE
BRAINSTEM
CEREBELLUM

Figure H-7

Sample Audiogram

KEY

O = RIGHT EAR
X = LEFT EAR
[] = BONE CONDUCTION
S = SPEAKER
A = AIDED

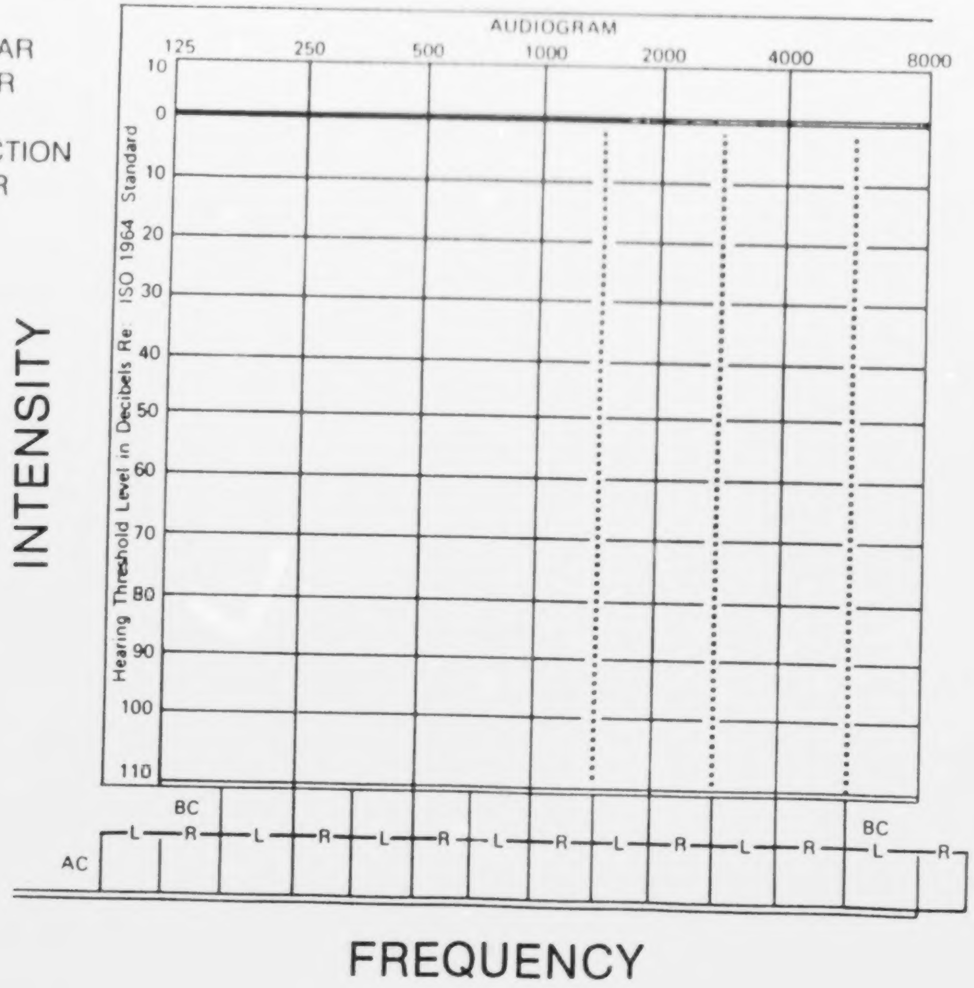
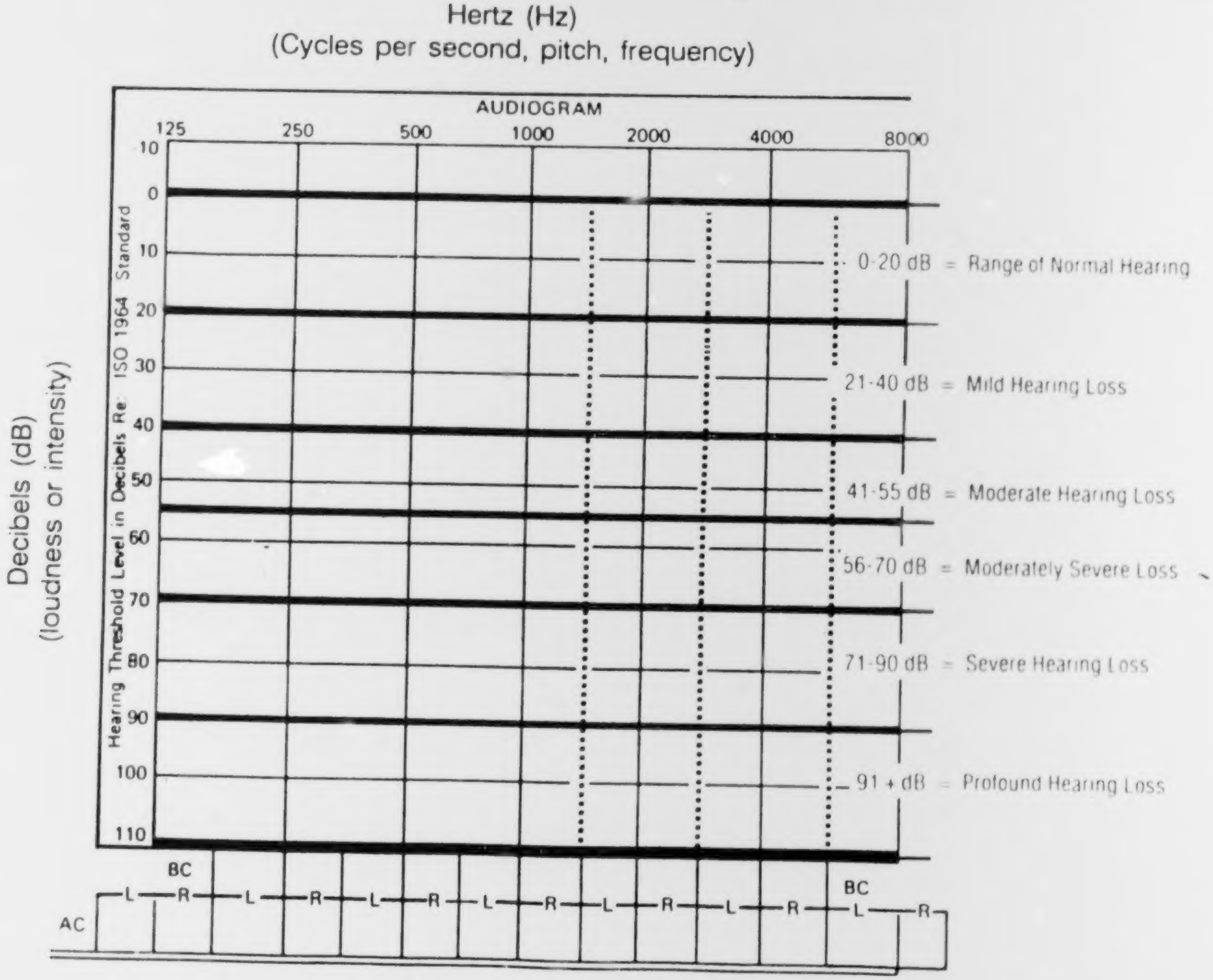


Figure II-1

Amounts of Hearing Loss



Degrees of Hearing Loss

	dB Threshold	Degree of Hearing Loss	Ability to Detect Speech	Familiar Sounds
Normal Hearing	0 10 20	**Normal**	Can hear speech with no difficulty	Rustling leaves Whisper
Hearing Impairment	30 40	**Mild**	Can hear speech unless distant or faint	Watch tick
	40 50	**Moderate**	Can hear conversational speech at 3 to 5 feet - needs hearing aid	Air conditioner
	60 70	**Moderately Severe**	Can hear *loud* conversations. has great difficulty in group situations	
	80 90	**Severe**	May hear loud voice about one foot away, may identify noises in environment, may distinguish vowels	Piano Food blender
	90 100 110 120 125	**Profound**	May hear some loud sounds	Lawn mower Jet at 1,000 feet Motorcycle Rock band
	125 130 140	**Threshold of Pain**		Jackhammer

Figure H-2

Comparison of the Frequency and Intensity of Various Environmental and Speech Sounds

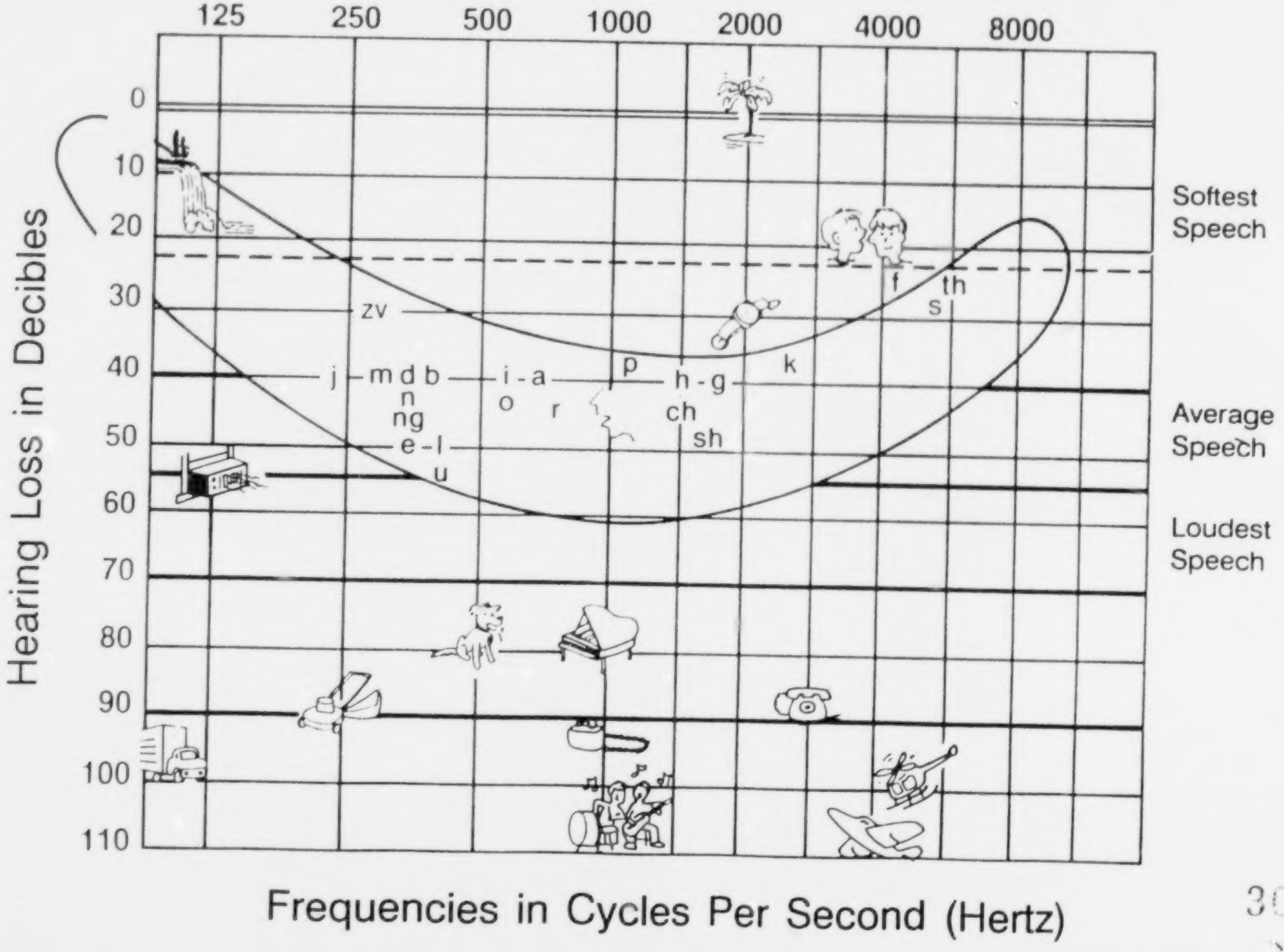


Figure H-8

Two Illustrations of Hearing Loss with a Flat Audiogram

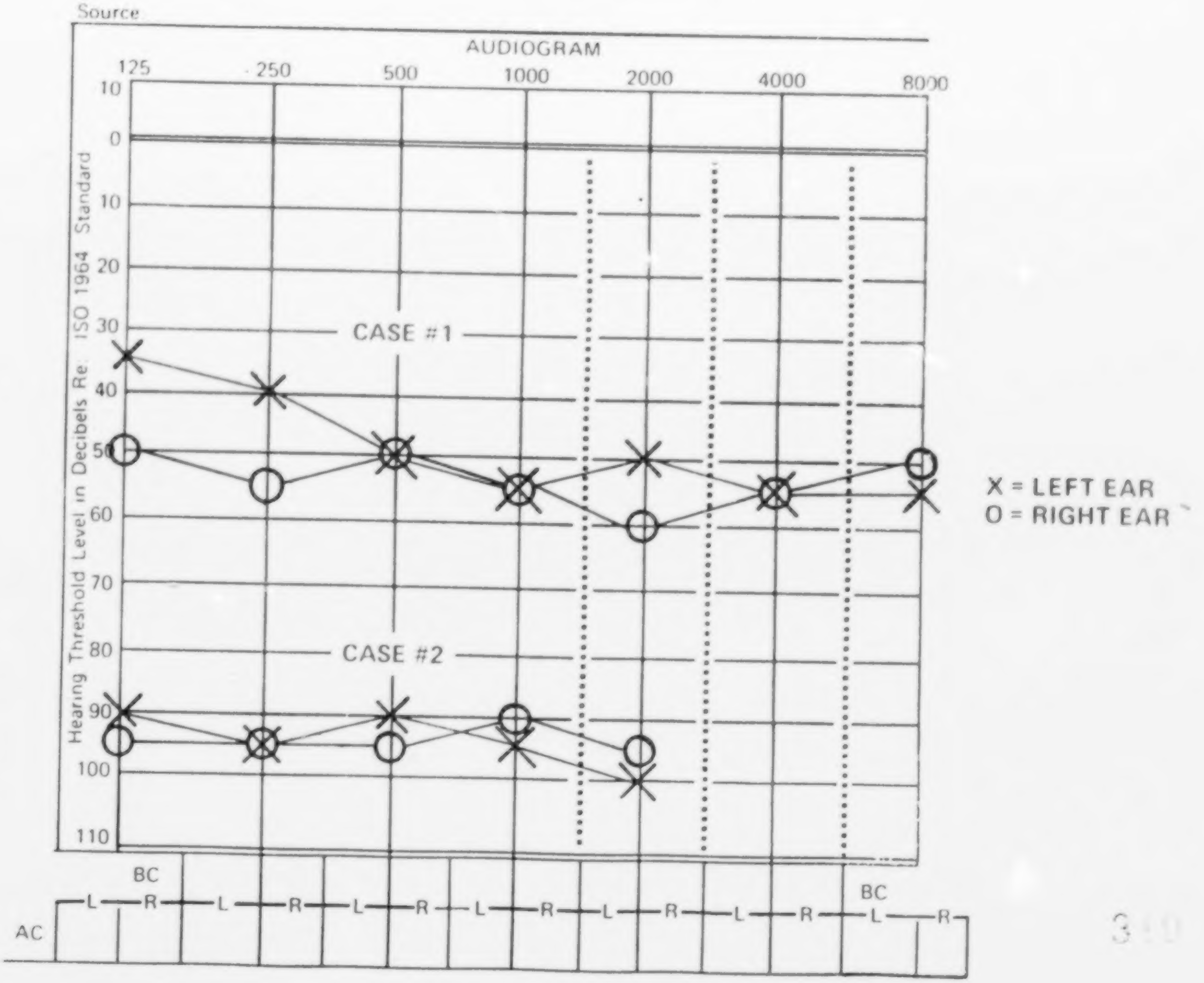


Figure II-9

Two Illustrations of Hearing Loss with a Sloping Audiogram

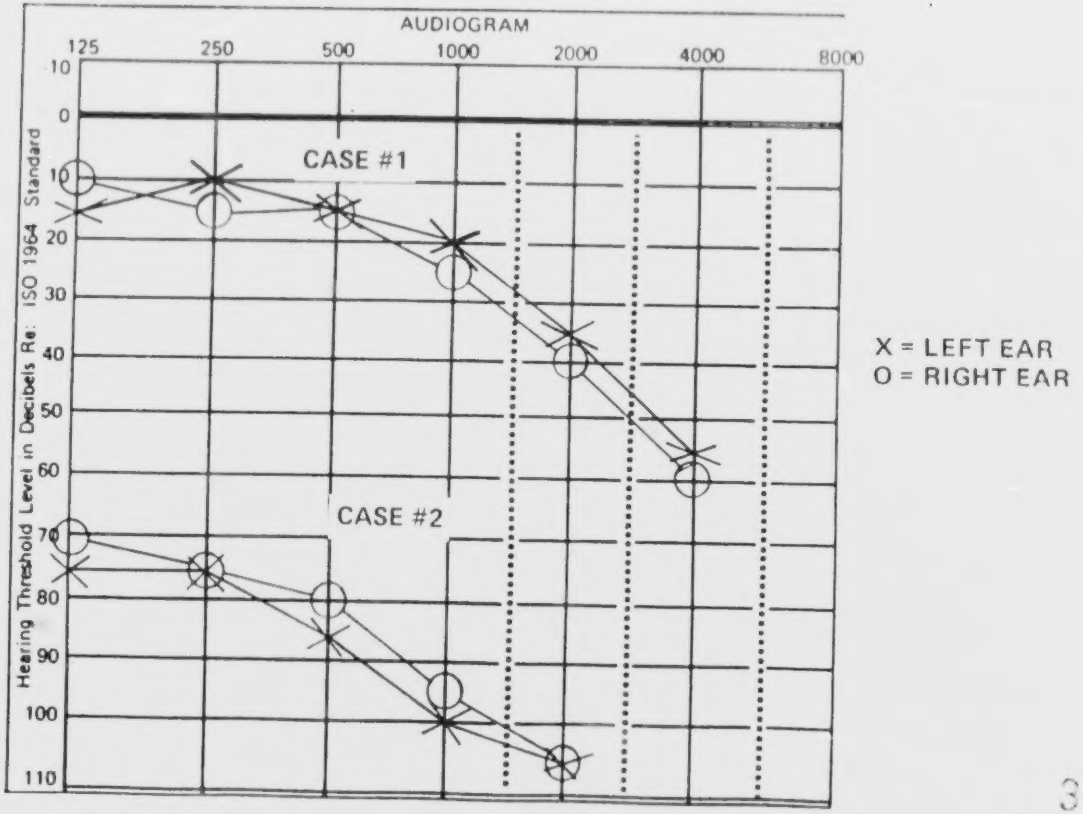


Figure H-14

Illustration of Conductive Hearing Loss

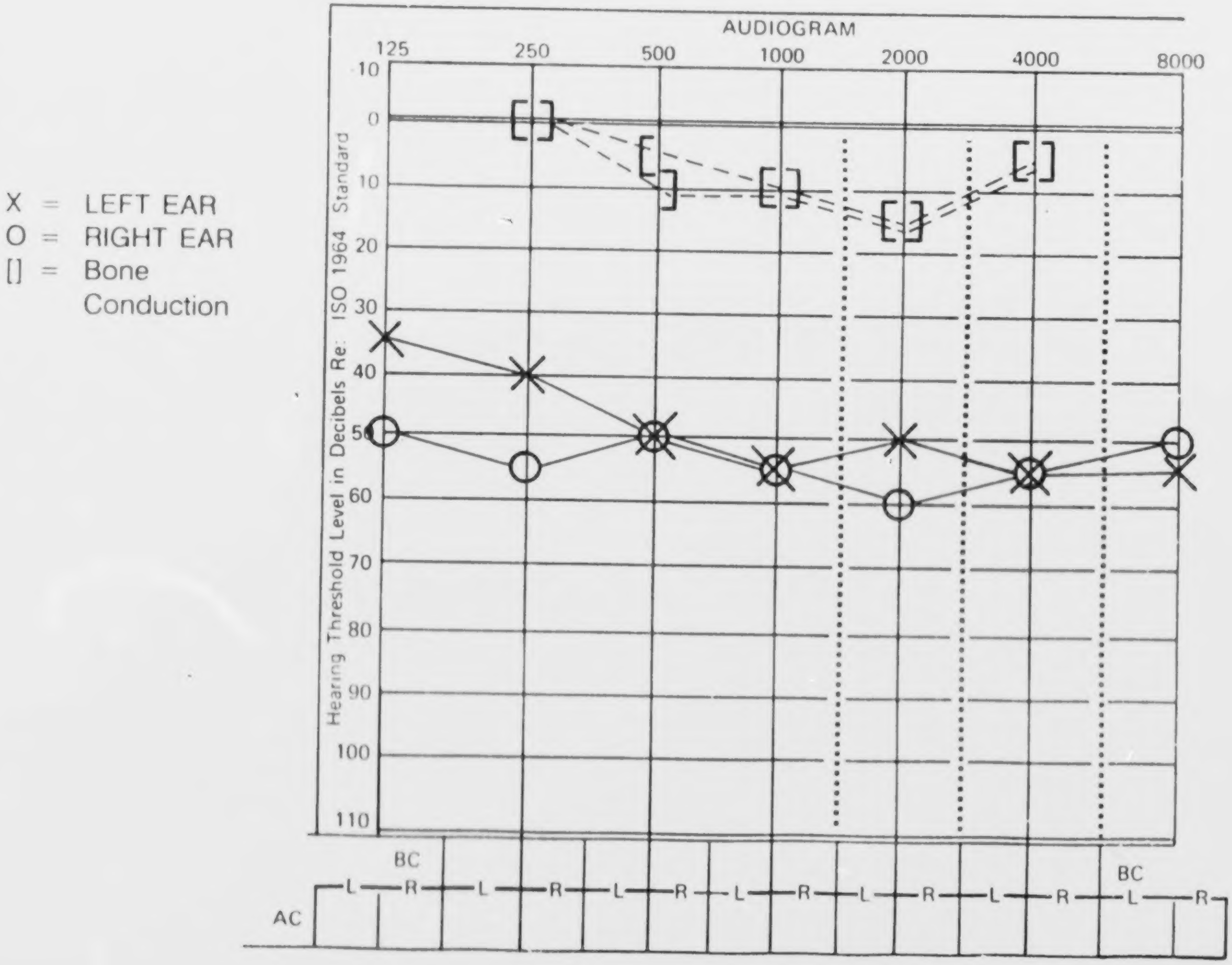
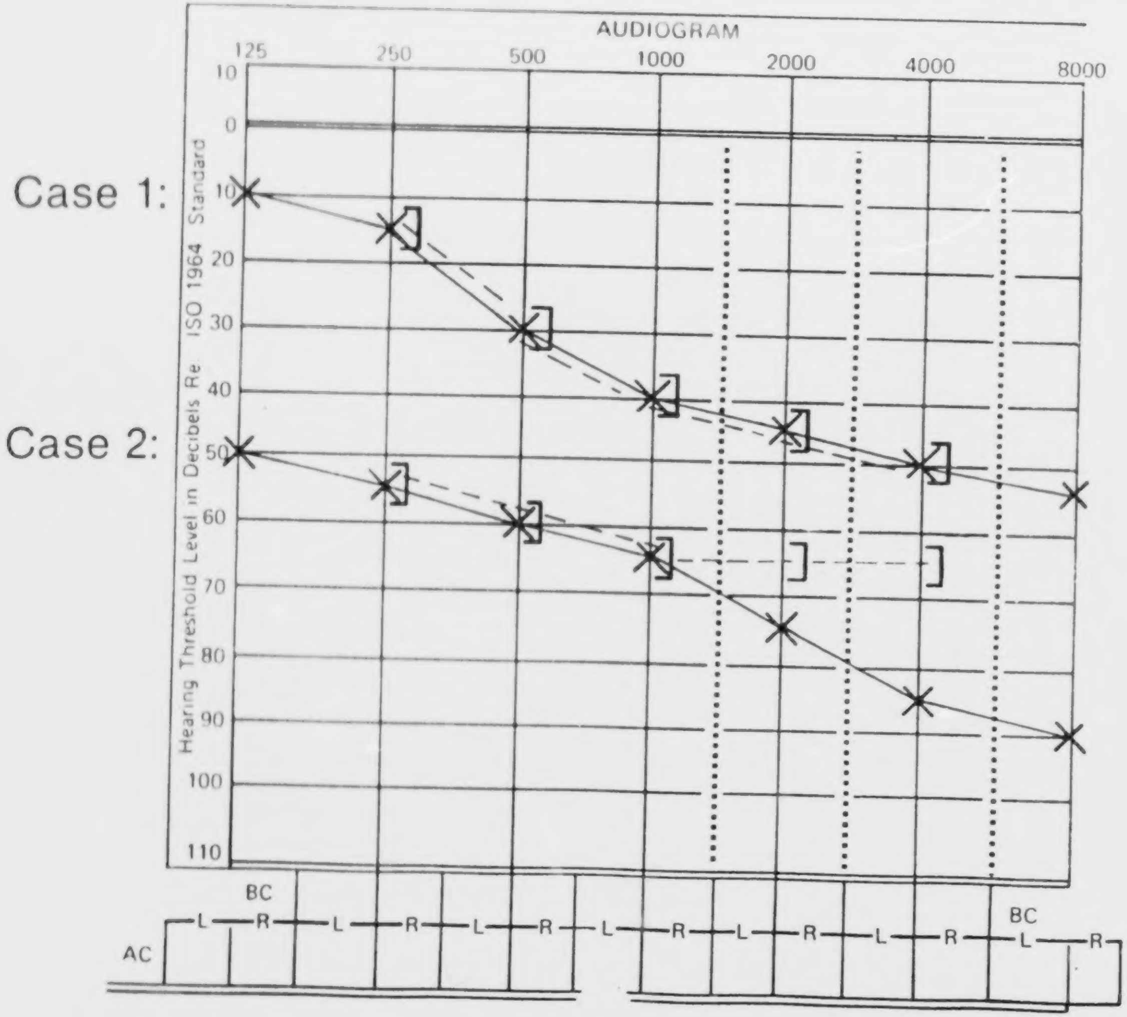


Figure H-15

Illustration of Sensorineural Hearing Loss



Activity:

Hearing Loss Simulations

Moderate Hearing Loss Simulation
Sensorineural/High Frequency
(Sentences)

1. ____

____

2. ____

____

3. ____

____

4. ____

____

5. ____

____

Sensorineural/High Frequency Hearing Loss
(Spelling Test)

Severe Hearing Loss

1. ____________________
2. ____________________
3. ____________________
4. ____________________
5. ____________________
6. ____________________
7. ____________________
8. ____________________
9. ____________________
10. ____________________

Moderate Hearing Loss

1. ____________________
2. ____________________
3. ____________________
4. ____________________
5. ____________________
6. ____________________
7. ____________________
8. ____________________
9. ____________________
10. ____________________

Mild Hearing Loss

1. ____________________
2. ____________________
3. ____________________
4. ____________________
5. ____________________
6. ____________________
7. ____________________
8. ____________________
9. ____________________
10. ____________________

Transcriptions for the Hearing Loss Simulations

Moderate Hearing Loss Simulation Sensorineural/High Frequency (Sentences)

1. It is tough to pass a calm pool on a hot day.
2. Please sell me a nice book with white pages
3. Walk back and knock on the ranch house door.
4. Your wife bought a fine chair after a long search.

Sensorineural/High Frequency Hearing Loss (Story)

Normal Hearing:

During the early 1900's, the busseling (sic) city of Mobile, Alabama, was experiencing its first automobiles. Auto drivers were terrible. They demanded to drive as they pleased. Their only concern was for their destination and getting there as quickly and as precisely as possible.

It was not uncommon to see an auto drive through someone's backyard, or through a vacant lot just to get somewhere faster. Drivers commanded the roads as they pleased and at the speeds they pleased. Collisions were frequent and damage to property was tremendous.

Mild Hearing Loss:

The City Fathers of Mobile became very concerned. They tried countless safety precautions, all without the slightest success.

If it hadn't been for Random Persons, a citizen of Mobile, the automobile problems would quite likely never have ended. And it all happened as the result of an unlikely string of events.

Random Persons was a salesman. He had spent a long, hot, and tiring day making sales calls far to the south. As he drove home, his mind constantly wandered from his driving. As he neared the edge of the city, he recalled later, he hit a series of bumps that startled him.

Moderate Hearing Loss:

The next morning, Random called the County Road Crew to report those road bumps of the night before. When the Road Crew arrived at the section of road reported by Random, they beheld a curious sight and smell. There in the exact center of the road and exactly five feet apart were a dozen white stripes.

It didn't take the Crew Boss long to see that the stripes were skunks which had been flattened and merged into the freshly oiled road.

Severe Hearing Loss:

It looked as though a family of skunks had been partaking in a familiar game of Follow-the-Leader, strolling down the highway only to be flattened into the road surface by Random's unattentive (sic) driving.

The scent from the flattened skunks easily persuaded the Road Crew to leave them be. As a consequence, motorists driving that stretch of road were forced to stay to the extreme sides of the road to avoid the strong odor.

Mild Hearing Loss:

The City Fathers were quick to see, and smell, the safety implications of the entire mishap. They were quick to observe that the white stripes divided the road and kept opposing traffic apart. The odor also kept everyone awake and moving along.

The City Fathers knew that they couldn't divide every road with skunks. Soon skunks would become extinct. So they simply painted white stripes in the middle of all Mobile roads. And it worked.

Soon an entire nation followed the Mobile example, dividing roads with painted white lines.

High Frequency Sensorineural Hearing Loss
(Spelling Test)

1. Bath
2. Pearl
3. Sour
4. Mouse
5. Learn
6. Wheat
7. Vine
8. Tape
9. Hedge
10. Mood

How Hearing Loss Affects Communication and Concept Development

How Hearing Loss Affects Communication and Concept Development

After having had two experiences involving hearing loss, how do *you* think hearing loss affects communication and concept development?

Communication Modes

HELEN KELLER NATIONAL CENTER
COMMUNICATIONS LEARNING CENTER

LANGUAGE LEVEL 1

CHARACTERISTICS

a. Minimal expressive and receptive communication skills
b. No formalized linguistic symbol system
c. May display behaviors of tactual defensiveness
d. May have no previous exposure to sign language
e. Methods of communication may include natural body gestures, object cues, environmental cues and establish daily routines
f. Limited past experience
g. Difficulty generalizing information across a variety of domains

INSTRUCTIONAL PROGRAMS

Language training (concept and skill development) must occur in the natural environment during "hands on" meaningful activities. Instruction most successful outside the domain of the classroom throughout the course of the day.

Personal Grooming Program
Meal Time Program
Leisure Time Activities
Work Training Program
Community Activities Program

OBJECTIVE EXAMPLES

a. Manipulates objects and persons to make needs known.
b. Accept molding of hand to form sign for functional objects in the environment during daily routine with a familiar person. Also attends to "speaker's" gestures and signs.
c. Responds appropriately to signed directions paired with concrete object during daily routine.
d. Identifies self using name sign or tangible symbol.
e. Pairs object with picture.
f. Indicates basic needs (toilet, drink, food), using sign, pointing to picture.
g. Indicates preference given a variety of objects representing choice of activity.

LANGUAGE LEVEL 2

CHARACTERISTICS

a. Adequate basic communication skills to make a variety of needs known.
b. Responds appropriately to concrete messages presented during daily routine.
c. May minimally initiate communication but can interact with others possessing common mode.
d. Language may be minimally descriptive.
e. Topics of communication are generally concrete and dependent upon past experience. Abstract ideas are difficult to comprehend or express.
f. Limitations or gaps in linguistic competence influences independence in other areas.
g. Supplemental communication aids or alternative methods are necessary.

INSTRUCTIONAL PROGRAM

1. Intensive one-to-one instruction in classroom domain
   a. Communication books
   b. Vocabulary development - sign, written, sight word
   c. Basic written language skills (language experience approach)

2. Opportunities to acquire skills in the functional domain (Community Neighborhood Experience) Communication with non-signing public

3. Conversation groups

OBJECTIVE EXAMPLES

1. Creates simple sentences using NOUN plus VERB structure while relating events of personal experience.

2. Responds appropriately to WH? (What, who, where, when)

3. Increases ability to interact with peers in a group situation - asks appropriate questions to gain additional information from others, elaborates on topics of conversation etc...

4. Utilizes communication book in a restaurant to order and pay for food

5. Increases functional sign vocabulary (foods, activities, feeling, cooking term, etc...)

6. Increase sight word identification for functional items, survival phrases, etc...

LANGUAGE LEVEL 3

CHARACTERISTICS

a. Possesses a strong preferred modality of communication (ASL or English)
b. Highly skilled in at least one method of communication
c. Must learn new modality of communication due to recent sensory loss (ex. braille vs. print, tactual sign language vs. visual sign language)
d. Onset and/or degree of sensory loss influences type of training pursued
e. Requires alternate techniques due to recent sensory loss so as to increase independence in the public domain

INSTRUCTIONAL PROGRAMS

a. Vocabulary development - sign, written, braille
b. Reading comprehension
c. Remedial English Grammar
d. Advanced written language skills
e. Spelling
f. Conversational sign language skills

OBJECTIVE EXAMPLES

a. Writes descriptive essay
b. Uses written language as an alternate method of communication in the public domain
c. Writes a business letter
d. Demonstrates adequate language skills to utilize aids and devices for communication purposes
e. Accommodates and adapts to other individuals with communication differences
f. Demonstrates ability to read and comprehend various publications, i.e.; newspaper, magazine articles for information and enjoyment purposes

LANGUAGE EVALUATION

A variety of formal and informal testing tools may be used to collect and evaluate language samples.

WRITTEN LANGUAGE

1. Cued language samples using pictures
2. Informal (natural) samples (i.e., notes, letters, autobiographies, journal entries)
3. Stanford Achievement Test

4. Gallaudet Diagnostic Test STEP
5. Basic "who","what", "when", "where", questions
. Test of Syntactic Abilities

ORAL/SIGN LANGUAGE

1. Conversation
2. Teacher directed commands
3. Vocabulary lists
4. Observation of sign language style: ASL, PSE, SEE, Gesture
5. Pictures/objects to elicit descriptive language
6. Pictures/objects to elicit question responses

READING COMPREHENSION

1. Basic "who", "what", "when", "where", questions
2. Selected paragraphs followed by discussion (i.e., re-tell the story)
3. Selected paragraphs followed by questions
4. Stanford Achievement Test

FUNCTIONAL APPROACH TO LANGUAGE INTERVENTION AND ASSESSMENT

Language is a Social Tool - the conversational approach to teaching language skills uses the environment.

You must manipulate variables in the environment to create opportunities for language learning. Training must occur in the functional environment inside events or during hands on meaningful activities.

The communication behavior taught must have a purpose. Preferable it is a high frequency behavior. This will enhance the generalization of this behavior.

You have communication before you learn language. A communication system motivates a person to learn language. A person must have a reason to learn symbols.

So, the first step is to establish a conventional communication modality (visual, auditory, tactile, mixed).

Pre-symbolic skills include

1. *Physical imitation*
2. *Object permanence*
3. *Turn taking*
4. *Functional use of objects*
5. *Gestures*
6. *Receptive language*

Non-symbolic Communication

1. *Body movements*
2. *Facial expressions*
3. *Tactile cues (ie: on the body touch cues)*
4. *Vocal sounds*
5. *Eye contact*
6. *Gestures*
7. *Imitation*

Emergency of symbol system

1. *More formalized gestures*
2. *Object cues*
3. *Basic signs iconic ------ arbitrary*
4. *Pictures - line drawings, photos*
5. *Signed phrases*
6. *Communication books*

Tying It All Together

Tying It All Together

Through this workshop you have found that there are four major areas of concern when working with Deaf-Blind individuals:

1. Anticipation
2. Motivation
3. Communication
4. Learning

Deaf-Blind individuals may:

* lack the ability to communicate with their environment in a meaningful way

* have a distorted perception of their world

* lack the ability to anticipate future events or the results of their actions

* be deprived of many of the most basic extrinsic motivations

* be unable to benefit from opportunities for secondary or tertiary learning

* have had medical problems that led to serious developmental lags

* have been mislabelled as mentally retarded/developmentally delayed or emotionally disturbed

* have been forced to develop unique learning styles to compensate for their multiple disabilities

* have extreme difficulty in establishing and maintaining interpersonal relationships with peers

* have been placed in inappropriate educational and adult programs designed to serve other developmental disabilities - such placements resulted in further developmental delays

What are some strategies when working with Deaf-Blind Adults?

1. Use one-on-one interaction initially
2. Provide constant, non-distorted information to the consumer
3. Use the consumer's communication system (signals and cues, coactive signing, interactive signing, pictures, Braille, etc...)
4. Make the task meaningful and relevant - provide motivation
5. Support
6. Adapted learning strategies.

Developing Communication for Children and Adults with Deaf-Blindness

Module #1:
Understanding the Special Communicative Needs of Consumers with Deaf-Blindness and Creating an Environment that Encourages the Development of Effective Communication

Prepared by Larry Rhodes, MS
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Dynamics and Etiologies of Deaf-Blindness

Before we can talk about establishing and then further developing communication for a consumer with deaf-blindness, we first need to define what we mean by deaf-blindness.

What is Deaf-Blindness?

"Deaf-Blind" refers to two sensory impairments, visual and hearing, occurring in combination with each other. The combination of these sensory losses causes significant education and rehabilitation problems. For the purpose of this training, we will use the Federal definition of Deaf-Blindness used to identify deaf-blind children. This is the definition used by Missouri's 307.11 (Deaf-Blind) Project.

The Federal Definition of Deaf-Blindness

> The term "Children with deaf-blindness," means children and youth having auditory and visual impairments, through combination of which creates such severe communication and other developmental and learning needs that they cannot be appropriately educated without special education and related services, beyond those that would be provided solely for children with hearing impairments, visual impairments, or severe disabilities, to address their educational needs due to these concurrent disabilities.

- The Federal Register,
October 11, 1991, page 51585

We are using the Federal definition in the training not only because it is the one used by the Missouri 307.11 Project but also because it is *functional*.

When you are working with a consumer with deaf-blindness, you need to ask yourself:

- Does this consumer have enough vision to compensate for her/his lack of hearing?
- Does this consumer have enough hearing to compensate for her/his lack of vision?

If the answer is *"NO"* to both of the above, you are working with a consumer with deaf-blindness.

The term "Deaf-Blind" does not always mean *totally* blind and *totally* deaf. Most consumers with deaf-blindness actually have some residual hearing and/or vision. We will describe the types of vision and hearing losses a little later.

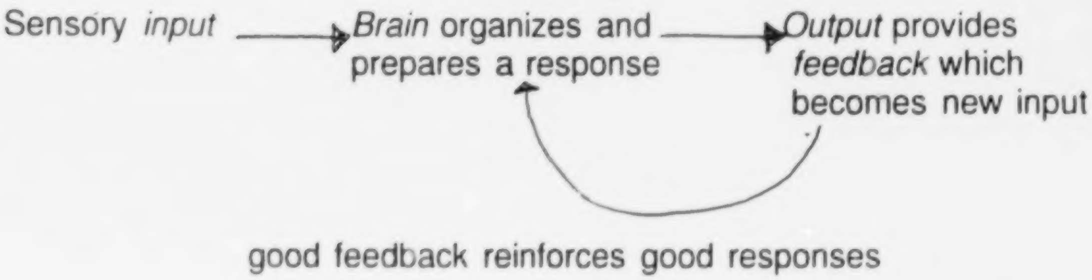
What makes the combination of deafness and blindness so unique?

Vision and hearing are our two *distance* senses; they bring the world to us. Loss of these two senses deprives us of the two primary senses through which we learn about the environment and the world at large.

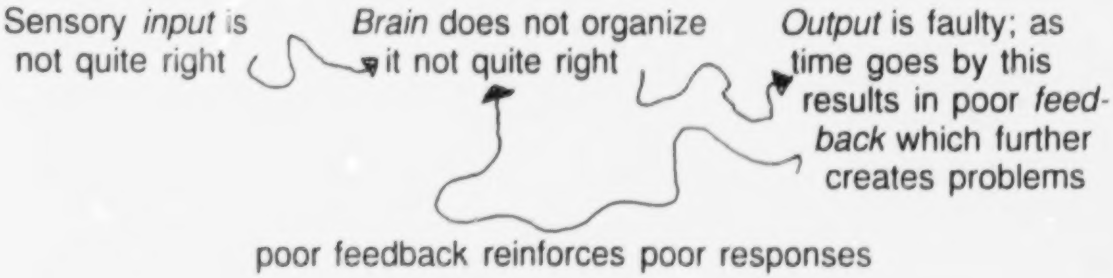
Because of these to losses - vision and hearing - the consumer with deaf-blindness, particularly if deaf-blind since birth, may experience cognitive problems that may resemble those experienced by consumers with developmental disabilities. Behaviors of a consumer who has been deaf-blind since birth may resemble those of a consumer with autism. This is because the consumer's incoming information about the world is distorted.

Below is a chart that provides a simple way of looking at sensory integration and how a combined vision and hearing loss can create cognitive delays. The diagram is a modification of one developed by Jean Ayers.

NORMAL


Sensory *input*
Brain organizes and prepares a response
Output provides *feedback* which becomes new input
good feedback reinforces good responses

DEAF-BLIND


Sensory *input* is not quite right
Brain does not organize it not quite right
Output is faulty; as time goes by this results in poor *feedback* which further creates problems
poor feedback reinforces poor responses

If, in addition, the consumer also has developmental disabilities or cerebral palsy, the poor feedback cycle is further reinforced.

Four Categories of Deaf-Blindness

The Federal Government and the 307.11 Projects group the causes of deaf-blindness into six groups. They are: Syndromes, Multiple Congenital Anomalies, Prematurity As a Sole Cause, Congenital Prenatal Disfunction, Post-Natal Causes, and Other. These groups are determined by the cause of the deaf-blindness.

For the purposes of this in-service, however, we will use the four categories of deaf-blindness that is used by the Helen Keller National Center for Deaf-Blind Adults and Youth. The system used by the Helen Keller National Center (HKNC) indicates *when* a consumer lost vision and hearing. Knowing when the vision and hearing losses occurred helps predict to some degree how much language the consumer may have, which language the consumer may have, which concepts the consumer may have fully or partially developed, and so on.

Here are the four groups:

1. **Congenitally Deaf, Adventitiously Blind**

This means that the consumer was born with a hearing impairment (or acquired one shortly after birth) and later lost some or all vision.
Some causes of vision loss:

Retinitis Pigmentosa (RP)/Ushers/Other Related
Macular Degeneration
Diabetic Retinopathy
Cataracts
Retinal Detachment

2. Congenitally Blind, Adventitiously Deaf

This means that the consumer was born with a vision impairment (or acquired one shortly after birth) and later lost some or all vision.

Some causes of hearing loss:

- *Unknown*
- *High Fevers*
- *Diabetes*
- *Kidney Failure*
- *Pollution/Toxins*
- *Trauma*
- *Genetic Factors*
- *Presbycusis*

3. Congenitally Deaf-Blind

This means the consumer was born with both a vision and a hearing impairment (or acquired both shortly after birth)

Some causes of congenital deaf-blindness:

- *Prenatal Disfunction:*
    - *AIDS*
    - *Rubella*
    - *Toxoplasmosis*
- *Syndromes*
    - *Down's*
    - *Trisomy 13*
- *Multiple Congenital Anomalies*
    - *CHARGE Association*
    - *Fetal Alcohol Syndrome*
    - *Maternal Drug Abuse*
- *Prematurity*
- *Pre- and Post Natal Trauma*

Meningitis
Encephalitis

4. **Adventitiously Deaf-Blind**

This means the consumer was born with neither a vision nor hearing impairment but later acquired both (either simultaneously or one at a time)

Some causes of adventitious deaf-blindness:
Illness
Trauma
Genetic Factors
Age related vision and hearing losses

At this point, we need to briefly examine vision and hearing losses. By understanding the functional problems resulting from vision and hearing loss, we can begin to understand the communication needs of consumers with deaf-blindness.

The Five Types of Vision Loss

Regardless of the *cause* of vision loss (Glaucoma, Cataracts, Retinitis Pigmentosa, etc), the consumer with deaf-blindness experiences one or more of the following five types of *functional problems*. Below is a brief description of the five types of functional vision problems.

Loss of visual acuity: This means that the consumer with deaf-blindness does not see as clearly (details) as consumers with normal vision.

Loss of visual field: This means that the area the consumer can see - above, below, to the sides, and straight ahead - is limited when holding her/his head and eyes still.

Loss of contrast sensitivity: This means that the consumer is unable to see the relative difference between the lightness and darkness of objects (something like looking at a faded photograph).

Loss of oculo-motor control: This means that the consumer has difficulty moving her/his eyes when visually fixating, following, and/or scanning objects.

Loss of visual processing: The consumer's brain is having difficulty making sense out of what she/he is seeing.

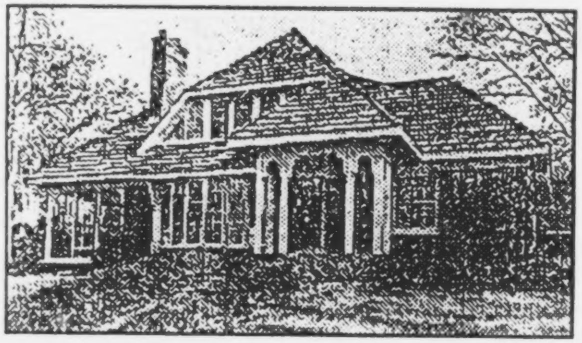
Often when we think of vision loss we think of only the loss of visual acuity and/or the loss of visual fields. Most Federal and state agencies - as well as many private programs and agencies - only look at a consumer's visual acuities and visual fields when determining eligibility for services and funding.[1] A consumer may have a cortical vision impairment (which results in the loss of visual processing) that interferes significantly with that consumer's ability to use vision and yet the consumer may not be eligible for services because cortical vision impairment can not be "measured" like visual acuities and visual fields.

---

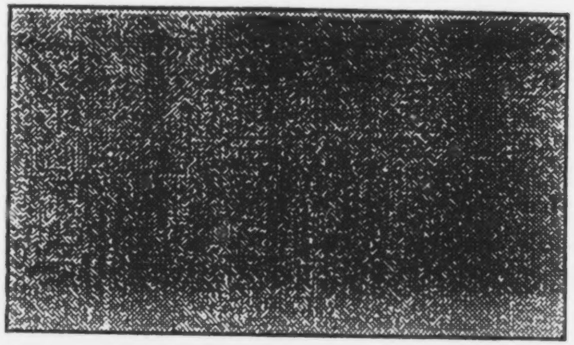
[1] One exception (of sorts) with the Federal Government is with the definition of Deaf-Blindness provided above. State 307.11 projects are not limited to using only visual acuities and visual fields when determining if a child should receive deaf-blind services.

HOW VISUAL LOSSES APPEAR

LOSS OF VISUAL ACUITY



Normal visual acuity lets us see sharp details of this house both close up and far away.



The loss of visual acuity causes 'blurry' vision. The child may be able to see the shape of something, but not the details.

A person has low vision if the acuity in his best eye with the best correction is between 20/50 and 20/200 (AFB).

A person is legally blind if visual acuity is 20/200 or worse in the better eye with the best correction possible.

In the U.S., One in 500 people are legally blind.

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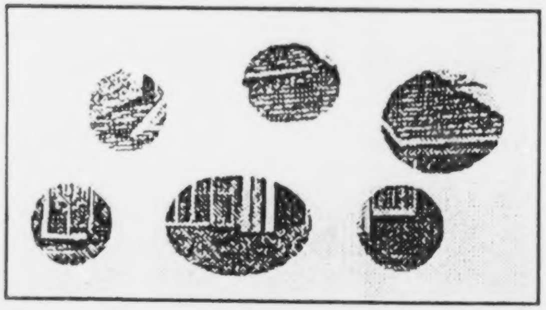
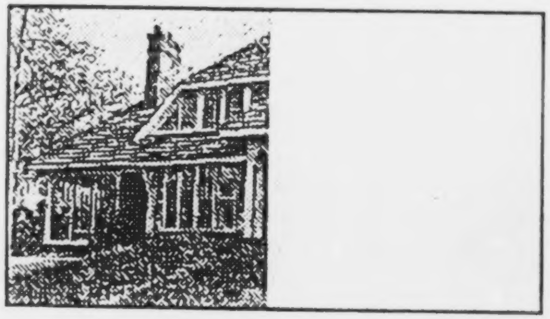
Diagram V-10 (cont.)

LOSS OF VISUAL FIELDS



'ISLANDS' OF VISION: a child with this type of field loss only sees islolated parts of people or things when he is looking at them. Like with scattered blind spots, the child's functioning will be determined by how big, how many, and where the islands of vision are.



HEMIANOPSIA: A child with this type of field loss only sees half of the people or things when he is looking at them. This half of visual field could be left or right or top or bottom. The child may not notice or bump into people or things 'hidden' in the half of the visual field that has no vision.

A person is legally blind if their visual field is 20° or less in the better eye with the best correction possible.

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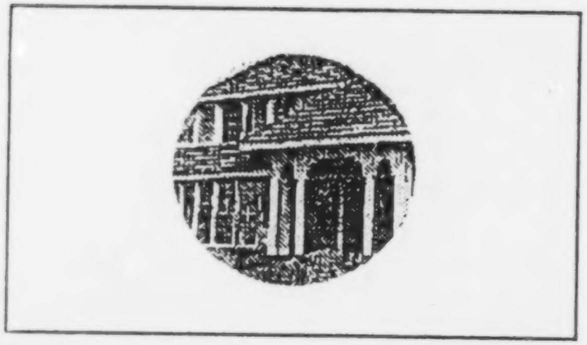
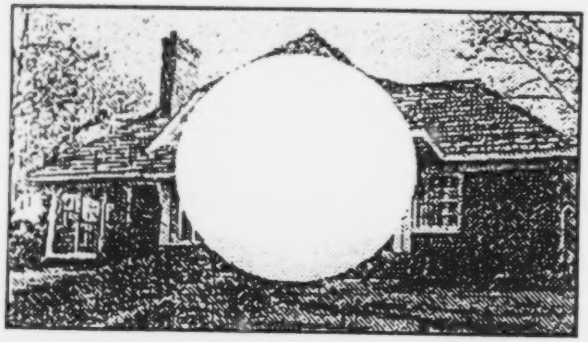
Diagram V-10 (cont.)

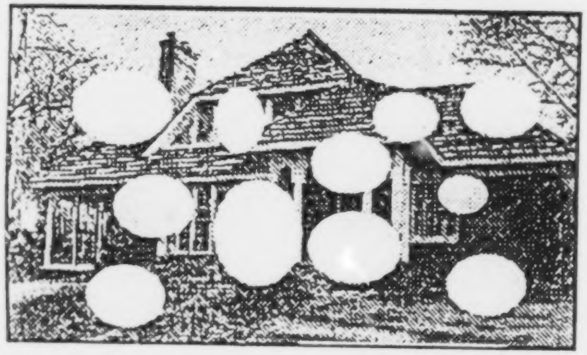
LOSS OF VISUAL FIELDS



LOSS OF PERIPHERAL ([redacted]) VISION: A child with this type of field loss will be able to only see straight ahead and will not be able to see people or things at the sides without turning his eyes or head. This is sometimes called tunnel vision. It is like looking through an empty tube of toilet paper.



LOSS OF CENTRAL VISION: A child with this type of field loss will only be able to see a blind or grey spot straight ahead no matter which way he turns his eye. It is like looking at a picture with a spot in the middle.



SCATTERED BLIND SPOTS OR SCOTOMAS: A child with this type of field loss may loose 'parts' of people or things when he is looking at them. How big the blind spots are, where they are located, and how many there are, will affect how severe the child's visual functioning will be.

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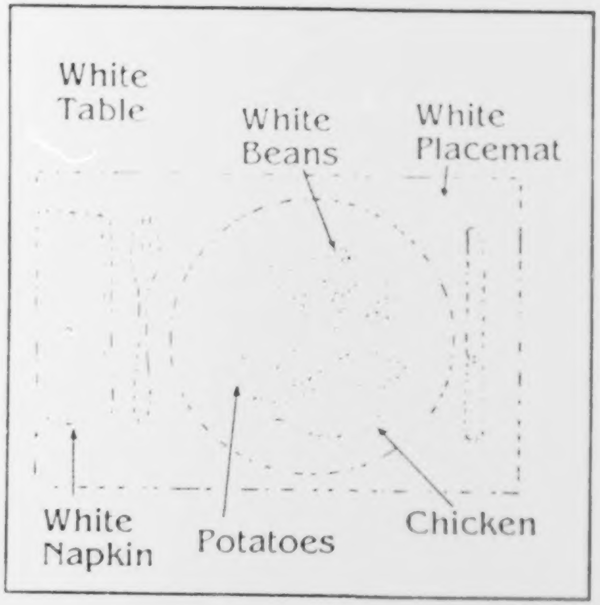
LOSS OF CONTRAST SENSITIVITY


White Table
White Beans
White Placemat
White Napkin
Potatoes
Chicken

CONTRAST SENSITIVITY is our ability to tell the difference between the lightness and darkness of things we see. It can also be explained as being able to tell things apart that are almost the same color.

To a child with the loss of contrast sensitivity, everything can appear 'washed out'. It's like looking at a faded photograph.

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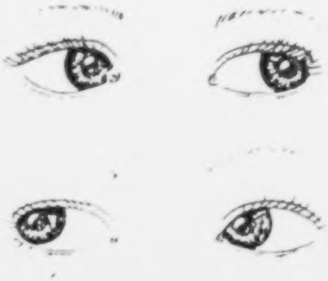
NORMAL GAZES

When you move your eyes straight up, each eye is being pulled by 2 muscles. One moves it up and in; the other moves it up and out. These are the superior rectus and inferior oblique muscles.

When you move your eyes straight down, the two muscles being used on each eye are the inferior rectus and superior oblique.

When you move your eyes up and to the left, the superior rectus and inferior oblique work together. On each eye, one muscle must exert a stronger pull than the other to achieve the turn to the left. In the left eye it is the inferior oblique; in the right eye, it is the superior rectus that pulls harder. The opposite would take place when looking up and to the right.

When you move your eyes to the side, just **one** muscle is exerting a pull on each eye. When looking to the left, the muscles exerting the pull are the external rectus in the left eye and internal rectus in the right eye.



When looking to the right, the internal rectus exerts the pull in the left eye and external rectus exerts the pull in the right eye.

When cross-eyed, the internal rectus in both eyes exerts the pull on each eye.

When looking down and left, the inferior rectus and **superior oblique** exert the pull in the left eye; the **inferior rectus** and superior oblique exert the pull in the right eye (underlined muscle exerts greater pull).

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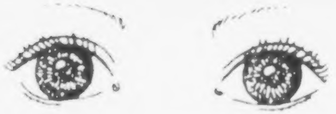
Diagram V-13

HETEROTROPIA OR STRABISMUS

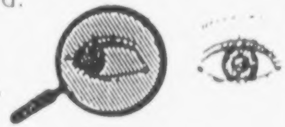
Phorias



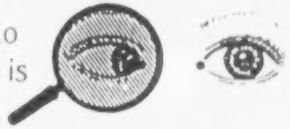
fusion keeps eyes straight

Exophoria A tendency for one or both eyes to turn out when fusion is interrupted.

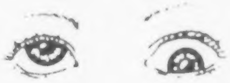
Cover right eye and it wanders to the right.



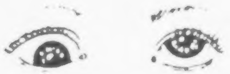
Esophoria
A tendency for one or both eyes to turn in towards nose when fusion is interrupted.



Right hyperphoria
Right eye tends to turn upwards; left turns downwards.



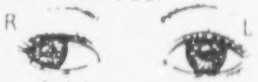
Left hyperphoria
Left eye tends to turn upwards; right turns downwards.



These can be overcome by natural desire for fusion. They can cause eye strain and headaches or blurred vision. Are not as serious as conditions in the right column nor are they as obvious. Correct with glasses, medication, patching, and/or surgery.

Tropias

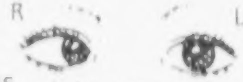
Exotropia
Turning outwards of one or both eyes, causing person to see double or suppress vision in one eye and use the other to see.



right exotropia

left exotropia

Esotropia
Turning inwards of one or both eyes causing the above.

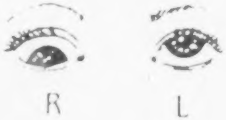


right esotropia

left esotropia

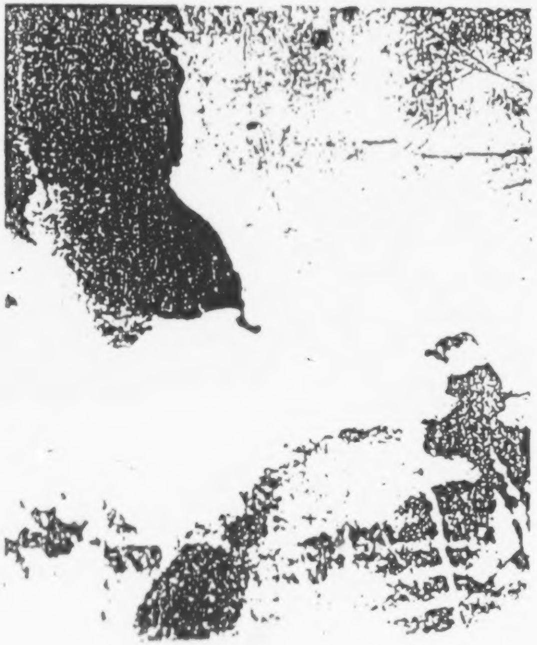
Right Hypertropia
Right eye turns upwards and left turns downwards causing the above.

Left Hypertropia
Left eye turns upwards and right eye turns downwards causing the above.



These conditions are worse in degree than the ones on the left and are obvious when looking at child's eyes. May be corrected with patching, glasses, medication, and/or surgery.

VISION IS MORE THAN 20/20 EYESIGHT



WHAT IS IT?
This fascinating picture is not an illusion.
It is an actual photograph of a familiar subject.

CAN YOU SEE IT ???

You may not immediately see the subject of the photograph on the reverse side because the seemingly meaningless blobs of light and dark require VISUAL interpretation. When you "see" the subject, you have VISION; before that you had only eyesight. Vision is the ability to get MEANING from eyesight.

Many people have clear "eyesight," but are slow readers, or have difficulty to get MEANING through the visual pathway. Such persons are handicapped in business, social and school life. Many also suffer visual discomfort or fatigue while reading or doing other close work.

The correction of these problems and the care of this complex physical and mental process called VISION require a highly specialized professional service - a service provided by the modern optometrist concerned with seeing as applied to clarity of eyesight AND the ability to get MEANING through vision.

Published in the interest of better vision by the Optometric Extension Program Foundation, Inc. (Nonprofit), Duncan, Oklahoma, an international organization dedicated to postgraduate education and research in vision.

SPIRIT INSTITUTE

Types and Degrees of Hearing Loss

There are three types of hearing loss: Conductive, Sensorineural, and Cortical/Perceptual. For conductive and sensorineural hearing loss, there are four degrees (mild, moderate, severe, and profound). There are no degrees for cortical/perceptual hearing loss.

Types of Hearing Loss	Degrees of Hearing Loss
Conductive	Mild
	Moderate
	Severe
	Profound
Sensorineural	Mild
	Moderate
	Severe
	Profound
Cortical/Perceptual	

Conductive Hearing Loss:

This hearing impairment is due to a disruption of the transmission of sound through the outer and middle ear.

This type of hearing loss can be caused by:

- blockage of the ear canal (by wax, some foreign object, etc.);
- blockage of the eustachian tube opening (by infection, allergy, etc);
- damage to the eardrum (by infection, blow to the heard, puncture by foreign object, etc.);
- damage to the three tiny bones in the middle ear (infection, etc.);
- congenital malformation of the middle ear (Pert's syndrome, Treacher Collins, Pierre Robin, etc.);
- congenital malformation of the outer ear; and/or
- any other situations that affect the outer and middle ear's ability to transmit sound waves to the inner ear.

The consumer can still hear sounds but they seem dull with little volume. Most speech sounds can be heard but they are softer. Words and sentences can be heard and understood better with the use of hearing aids or other types of amplification.

Sensorineural Hearing Loss:

This hearing impairment is due to sensory or nerve damage in the inner ear, the auditory nerve, and/or the brain stem.

This type of hearing loss can be caused by:

- illness (such spinal meningitis - bacterial, viral, and/or fungal, rubella, and other viral/bacterial/fungal infections);
- hereditary (in most cases is it damage to the cochlea);
- Rh factor;

- trauma;
- extremely loud noises;
- syndromes (CHARGE Association, Waardenburg, Pierre Robin, etc.);
- drugs (pre and/or post);
- prematurity; and/or
- anoxia (lack of oxygen at birth).

Not always, but many consumers with a sensorineural hearing loss experience the loss of only certain frequencies - generally the high frequencies. Sounds are distorted, even with the consumer wearing hearing aids or other types of amplification. Not all speech sounds can be heard. Words and sentences can be difficult or impossible to understand though listening alone. The consumer's perception is that the volume of sound is greatly reduced.

Understanding How the Degrees of Conductive and Sensorineural Hearing Losses Affect Speech and Spoken Language:

If the consumer has a mild hearing loss, the consumer may have trouble hearing faint or distant sounds/speech.

If the consumer has a moderate hearing loss, the consumer may not understand speech unless it is loud. The consumer may have difficulty in understanding speech in group discussions or when several people are talking. If the consumer had the moderate hearing loss before the age of two years, the consumer's speech may be defective.

If the consumer has a severe hearing loss, the consumer may hear a very loud voice - if it is within a foot of the consumer's ear. The consumer may be able to discriminate vowels but will have difficulty discriminating many consonants. The consumer's speech/*spoken* language will be adversely affected and will not develop spontaneously if the hearing loss occurred before the age of two years and if the consumer did not have hearing aids or other amplification. The consumer may use residual hearing to identify loud environmental sounds.

If the consumer has a profound hearing loss, the consumer may be able to hear loud sounds, but may actually be more aware of vibrations than of tonal patterns. The consumer generally will rely on vision than on hearing as the primary way of communication. Speech/spoken language will *not* develop spontaneously if the hearing loss occurred before the age of two years - even with the use of hearing aids and/or other amplification.

Cortical/Perceptual Hearing Loss:

This hearing impairment is due to damage to the auditory cortex and/or other parts of the brain used to process sound (such as the frontal lobe, parietal lobe, etc.).

This type of hearing loss can be caused by:
- anoxia (lack of oxygen at birth);
- prenatal infections (such as rubella, etc.);
- birth trauma;
- post natal trauma;
- prematurity;
- drugs (bòth pre- and post natal);
- Rh factor; and/or,
- brain diseases

How a consumer with a cortical hearing hears depends on which part of the consumer's brain is affected. If the auditory cortex is affected, the consumer may have difficulty analyzing sounds, remembering sounds, and choosing which sound to attend. If the frontal lobe is affected, the consumer may have expressive aphasia which means that the consumer can understand language but not be able to produce it. If the parietal lobe is affected the consumer may be unable to process experiences and therefore not be able to use language. If the temporal lobe is affected, the consumer may not be able to attach meaning to sound and/or attend to sound.

Describe the functional vision and hearing of the consumer with deaf-blindness you are serving:

Understanding the Communication Needs of Consumers with Deaf-Blindness

There are four major areas of concern when working with consumers with deaf-blindness:

1. Anticipation
2. Motivation
3. Communication
4. Learning

It is difficult to address one of the four areas without significantly impacting upon the other three.

In this and the workshops to come, we will address the communication needs of consumers with deaf-blindness. You will find that in addressing the communication needs of these consumers, we will be working directly with activities addressing anticipation, motivation, and learning.

When communication (and the other three ares of concern) is not properly addressed, consumers with deaf-blindness may:

* lack the ability to communicate with their environment in a meaningful way

* have a distorted perception of their world

* lack the ability to anticipate future events or the results of their actions

* be deprived of many of the most basic extrinsic motivations

* be unable to benefit from opportunities for secondary or tertiary learning
* have had medical problems that led to serious developmental lags
* have been mislabelled as mentally retarded/developmentally delayed or emotionally disturbed
* have been forced to develop unique learning styles to compensate for their multiple disabilities
* have extreme difficulty in establishing and maintaining interpersonal relationships with peers
* have been placed in inappropriate educational and adult programs designed to serve other developmental disabilities - such placements resulted in further developmental delays

According to the SKI*HI Institute at Utah State University, communication joins consumers with their world. It allows them to share ideas, wants, observations, feelings with others. By its definition, communication is dialogue - the exchanging of messages - between more than one persons. Without the ability to communicate, consumers with deaf-blindness are isolated from the world. It brings meaning to their world. Communication enables these consumers to have control over their environment.

In communication, one person sends a message and the other receives it. The sender of the message can send the message in many different ways besides just speech: body language, behaviors (good and "bad"), pictures and photos, touch, gestures, manipulation of people and objects, sign language, and so on. The receiver of the message can perceive the message in many different mays:

through the eyes, through the ears, through touch, and so on.

For a consumer with deaf-blindness, the means of communication may be very different from that of a consumer with no sensory, motor, and/or intellectual impairments. It is important to establish an effective communication system for a consumer with deaf-blindness if one is not already being used. If one is already being used, it is important to utilize that consumer's system and then to expand it.

Communication is learned by everyone through interacting with their environment. It starts in infancy when our parents attach meaning to our behaviors and then reinforce our responses throughout daily interactions (preintentional and intentional behavior). However, the hearing and vision losses of consumers who have these losses may sabotage that process. As infants, these consumers may not respond in ways typical of infants with normal vision and hearing. Their parents may misinterpret their infants' atypical responses. These infants, therefore, may later develope unusual patterns of communication and "behaviors".

According to the SKI*HI Institute, three key factors must be present for a consumer with deaf-blindness to learn to communicate effectively:

1. The consumer needs nurturing relationship with others.

2. The consumer needs to have things, experiences, and wants about which to communicate.

3. The consumer needs to be in a situation where other key people are using communication forms which the consumer can understand and use.

Establishing an Effective Communication System for Consumers with Deaf-Blindness

Assessing an Consumer's Present Forms of Communication:

Unless you are working with an infant or a very young child, the consumer you are serving already has some form(s) of communication established. When establishing an effective communication, it is always best to start with the form(s) the consumer with deaf-blindness already understands and uses.

These next two exercises are designed to help you learn about your consumer's form(s) of communication.

Communication
Informal Assessment

Questions to ask are:

1. *How* is the consumer communicating now?

2. *What* does the consumer communicate now?

3. Where does the consumer communicate? With whom? In what situations?

4. What does the consumer appear to be *unable* to communicate?

5. Does the consumer persist in attempting to communicate?

6. What do others feel the consumer needs to be able to communicate more effectively?

7. What do others need in order to be able to communicate with the consumer?

8. What are the future plans for this consumer?

Modified from: Bootorf, L. & DePage, D. (1982). Initiating communication systems for severely speech impaired persons. Topics in Language Disorders, 55-71.

COMMUNICATION INTENT MAP
for

____

When I do this...	I'm trying to tell you this...

COMMUNICATION INTENT MAP
(Continued)

When I do this...	I'm trying to tell you this...

Creating an Environment that Encourages the Development of Effective Communication

It is important when working with a consumer with deaf-blindness to create an environment that provides the consumer with opportunities to develop communicatively. The consumer must have the kinds of interaction (both with people and objects) and learning experiences needed to foster the development of communication. Creating such an environment takes into consideration the four areas of concern when working with consumers with deaf-blindness (anticipation, communication, learning, and motivation). The purpose of this section of the workshop is to share with you what is needed to create such an environment. You will later be provided with some tools you can use to ensure that you are creating such an environment.

Creating an environment that encourages the development of effective communication will be explored during this in-service and several of the subsequent in-services.

The Physical Environment:

There are three things that can make it hard for a consumer with a hearing loss to hear:

- distance between the consumer and a speaker is too great,
- the speaker's voice is too soft or too loud; and,
- there is distracting or masking background noise.

When you are providing services to a consumer with deaf-blindness, have you noticed that the consumer attends to you better when you are within a few feet of the consumer? What happens when you try to communicate with the consumer as you move further way? Does the consumer tend to "ignore" you or misunderstand you? Is this particularly true if there is also background noise (other conversations, a TV or radio playing, etc.)? Generally, it is best to have your head at the same level as the consumer you are serving and at a distance no greater than 3 - 4 feet.

If you have the opportunity to observe the consumer you are serving interacting with others, closely watch the consumer's reactions to the other's voices. How does the consumer react to loud voices? How does the consumer react to soft voices? Does this provide you with some idea of what voice level the consumer prefers?[2]

If the consumer you are serving has a conductive and/or sensorineural hearing loss and is wearing hearing aids or is using other amplification, it is important to remember that the hearing aids amplify *all* sounds. The hearing aid not only amplifies your voice, but also the voice of others in the area, a dog barking in the next room, a radio or TV, etc. The consumer may have a hard time sorting out your voice from all the other distracting noises. If the consumer has a cortical auditory impairment, competing sounds and voices may make it very difficult or impossible for the consumer to focus on the speaker. Many consumers with deaf-blindness who have some residual hearing enjoy listening to music (radio, TV, stereos, etc.) and/or enjoy listening to human voices. However, background music and voices may still be distracting to the consumer. If the consumer takes delight in listening to background music, etc., consider making this available to the consumer you serve during recreation and social periods. Consider eliminating - or at least minimizing them, during times when it is critical for the consumer to be able to focus on you and your voice.

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[2] Word of caution: If the consumer with deaf-blindness tends to dislike interaction with a person with a loud voice, be careful in your assumptions. If the person with the loud voice is also somehow "invading" the consumer's personal space, the consumer may be reacting to the invasion rather than only the loud voice. A consumer may, in fact, *prefer* loud voices because they can be heard better.

Assignment for next training:

Complete the form found on the next page and bring with you to the next in-service.

Identifying Distracting Sounds in the Environment

Name of consumer with deaf-blindness whom you serve

1. Generate a list of background noises occurring in areas where the consumer with deaf-blindness works, plays, etc:

   the classroom/workroom?

   the lunch room?

   the home?

   the car/van?

   other area(s) - please identify?

2. If the consumer whom you are serving wears a hearing aid or uses some other amplification device, listen to these competing background noises through the consumer's hearing aid. If you have a blindfold, put that on as well. How do these background noises affect you? Which do you find distracting?

3. Work to reduce the background noises. If several of you serve the same consumer with deaf-blindness, discuss how to eliminate the sources of these background noises. Record below the type of background noise eliminated and you eliminated it.

4. Now observe the behaviors of the consumer you serve with the changes in made. What are these behaviors? Are any changes noticeable? Did you eliminate completely a particular background noise that the consumer, in fact, enjoyed? Are there any noises that should be eliminated during certain activities, but maybe should be present for other activities? Record your observations and decisions below:

Glasses and Hearing Aids:

At the next in-service, we will explore how the environment can affect visual functioning (and behaviors) as well as how to modify the physical environment to enhance visual functioning. You will be shown how to take care of glasses at that time.

How to take care of hearing aids and how to do a daily hearing aid check will also be covered at the next in-service.

Creating Trust:

Earlier in this workshop, we briefly discussed the four major areas of concern when working with consumers with deaf-blindness. These areas are anticipation, communication, learning, and motivation. They are all interrelated. To effectively address these four areas, there must be a bonding - trust - between the consumer with deaf-blindness and the people who interact with that consumer.

Bonding:

Bonding is a connection or tie between two individuals. Bonding is vitally important when trying to develop effective, positive communication. A consumer with deaf-blindness is bonded with you when the consumer feels secure in the relationship with you. You will know that the consumer senses security in this relationship with you by the quality and frequency of the consumer's communicative attempts.

Probably the easiest - most important - way to establish bonding is to recognize the consumer's attempts at communication and respond appropriately to them. Earlier in this in-service, you had to do two exercises that helped you identify, enumerate, and then interpret some of these attempts at communication. You should continuously add to these lists.

On the next page is a form that can help you check to see if you are responding consistently to communicative attempts by the consumer you serve. At this time, break into your teams. One person in each team should volunteer to be checked while the other members of the team will observe the person and the consumer with deaf-blindness for the next half-hour of the in-service.

The in-service will continue, but the non-volunteer members of the team should keep watch to see if: 1) the consumer you serve is making an attempt at communication, and 2) if the volunteer responds to the attempt.

Arrange yourselves so that the consumer you serve is closest to the volunteer.

Once each team has identified a volunteer and has arranged itself as per instructions, notify the presenter that you are ready so that the in-service can continue. As the presenter continues to facilitate the in-service, the volunteer in each team will need to keep one eye/ear open for any communicative attempts by the consumer being served by each team. The observers in each team need to keep one eye/ear open not only for the communicative attempts by the consumer but also for the responses/non-responses of the volunteer.

At this time, we are not interested in if the volunteer's responses are appropriate - we are only interested in whether or not a communicative attempt is being missed.

Touch:

Through touch alone - without words or voice - we can convey affection, disapproval, anger, and so on. Even the lack of touch is powerful. By definition, deaf-blindness means a complete or partial loss of hearing and vision; these losses alone often require an increase in the amount of touching between the consumer with deaf-blindness and others. Touching may be needed to establish contact between the consumer with deaf-blindness and others. Many consumers with deaf-blindness needed physical assistance when transferring from one chair to another, walking, eating, toileting, and so on. Some consumers with deaf-blindness are "shown" what to do by using co-active and/or hand-over-hand techniques. Often people around these consumers may be reluctant to touch the consumers due to the cultural mores regulating touching.

You can easily communicate your moods to the consumer you serve through your touch. If you have an important appointment after work and you're late getting the consumer you serve ready to leave, are you inadvertently conveying this to the consumer? What kind of message(s) are you inadvertently giving to the consumer?

At this time, quickly find a partner. Decide who will be Partner A and who will be Partner B.

Start off with Partner B going under the blindfold. Partner A now needs to convey the following messages through touch to Partner B. Then Partner B must tell Partner A what each message is perceived to be. Once Partner A is finished, switch. Partner A goes under the blindfold and Partner B needs to convey the next set of messages to Partner A

Partner A's Messages to Partner B:

(NOTE: Make sure your touching is appropriate!)

1. Partner B came into your room somewhat upset this morning. You are not sure what is happening. You want to convey to your partner that you "are here for her/him."

2. You need Partner B to remain seated while you run into the next room to get something.

Partner B's Messages to Partner A:

(NOTE: Make sure your touching is appropriate!)

1. Partner A has been rather playful all morning - and it has been delightful to be around her/him - however, now you need to communicate to your partner that she/he needs to focus on the task at hand.

2. You've had a good day with your partner and you want to convey this to her/him before you both leave for home.

References

Alsop, L., ed., *A Resource Manual for Understanding and Interacting with Infants, Toddlers, and Preschool Age Children with Deaf-Blindness.* SKI*HI Institute/Utah State University, H.O.P.E., Inc., 1993

Watkins, S., ed., *The INSITE Model: A Model of Home Intervention for Infant, Toddler, and Preschool Aged Multihandicapped Sensory Impaired Children.* SKI*HI Institute/Utah State University, HOPE, Inc., 1989

Consumer to Staff Communicative Attempt Observation Form

Consumer Communication		Staff Communication	
Attempt #	Brief description of attempt	Staff responded	Staff did not respond
#1			
#2			
#3			
#4			
#5			
#6			
#7			
#8			
#9			
#10			
#11			
#12			

Continued

#13

#14

#15

#16

#17

#18

#19

#20

#21

#22

#23

#24

#25

#26

#27

MISSOURI 307.11 PROJECT
Workshop/Training Evaluation

Session Title: **Developing Communication for Children and Adults with Deaf-Blindness: Module #1:**

Presenter(s): **Larry Rhodes**

Date: **11 September 1996** Location: **Progressive Community Services**

Your Agency: ______________________________

Your position/title: ______________________________

Using the scale given below, please circle the number to evaluate the following statements/questions:

(1) Strongly Disagree (2) Disagree (3) Neutral (4) Agree (5) Strongly Agree

1. **The content of this session was consistent with the title/description found in the workshop/training announcement.**

(1) (2) (3) (4) (5)

2. **The level of difficulty was appropriate.**

(1) (2) (3) (4) (5)

3. **This session provided me with new knowledge and/or skills.**

(1) (2) (3) (4) (5)

4. **The presenter used the allotted time efficiently.**

(1) (2) (3) (4) (5)

5. **The style of presentation was conducive to learning.**

(1) (2) (3) (4) (5)

6. **The presenter made good use of examples and illustrations.**

(1) (2) (3) (4) (5)

OVER

7. **The presenter demonstrated a thorough knowledge of the subject matter.**

(1) (2) (3) (4) (5)

8. **I would enjoy attending another session from this presenter.**

(1) (2) (3) (4) (5)

9. **Teaching aids (slides, audio/visual tapes, handouts, etc.) were effective.**

(1) (2) (3) (4) (5)

10. **There was adequate time provided to allow satisfactory coverage of this topic.**

(1) (2) (3) (4) (5)

11. **Physical facilities (room, lighting, sound, temperature, etc.) were satisfactory.**

(1) (2) (3) (4) (5)

12. **This session provided knowledge/skills which I feel will make a difference in my work.**

(1) (2) (3) (4) (5)

13. **I intend to apply this information in the following way(s):**

Other comments regarding this session:

file name: txevaldbp

ACTION PLAN

Task	Person(s) Responsible	Due Date	Task if completed if...

ACTION PLAN

Date:

Team: ____

____

Task	Person(s) Responsible	Due Date	Task if completed if...